"It could be worse, I could be up a tree": The experiences of gay men living long term with HIV

Alison Wells

Thesis submitted in part fulfilment of the requirements for the qualification of Doctorate of Clinical Psychology, The University of Edinburgh

2nd April 2008

UNIVERSITY OF EDINBURGH / NHS (SCOTLAND)
CLINICAL PSYCHOLOGY TRAINING COURSE

SUBMITTED ACADEMIC WORK
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SMALL SCALE RESEARCH	☐ ☐
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Alison Wells

I declare that I am the sole author of this thesis and that the work contained herein is my own. This thesis, or any part of it, has not been submitted for any other degree or professional qualification

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ACKNOWLEDGEMENTS

I would like to thank the men who were involved in this study. I enjoyed meeting them and hearing their stories. Their openness and honesty made an impact upon me and I hope that is conveyed in this work.

Thank you to the agencies who helped: SOLAS/Waverley care, Positive Voice, Positive Help, Gay Men's Health, Healthy Gay Scotland, CHIV team, RIDU, the GUM clinic and the LGBT centre for health and well-being. Without their help I would not have been able to recruit, have the degree of understanding I have about HIV or have had anywhere to meet the men.

I would also like to say thank you to Paul Flowers who gave a few of us a great introduction to IPA and answered the odd question specific to my research. Also thank you to David Gillanders who kept me straight on the practicalities and process.

A big thank you to my proofreader, Anna, your support and words of wisdom were welcomed. A big thank you to Christine for the constant stream of e-mails and phone calls so I knew I wasn't going through this alone, and to Alina for sharing the bad times.

A big thank you to Chris Hewitt who has been amazing at maintaining my enthusiasm for this piece of work and also for containing my many anxieties. Thank you for the hours of supervision, for the proof reading and for the time to think and talk.

As always, thank you to my mum and dad, not just for the proof reading. And finally a huge thank you to Esha, the star who had to cope with me being tied to a laptop when I would rather have been having fun. Your love and support enabled me to complete this research and makes me smile.

ABSTRACT

Background: Receiving a positive HIV test result prior to 1996 was a diagnosis of terminal illness. This frequently had dramatic psychosocial effects on those receiving the diagnosis. The introduction of Highly Active Anti-Retroviral Therapy (HAART) in 1996 meant that HIV was no longer viewed as a terminal illness but was rather considered as a chronic manageable condition. As a result, it was felt that the ways in which people living with HIV were supported therefore changed due to a treatment option being available. For example, non-medical supports were reduced and in medical settings some patients reported that the focus of consultations became less holistic. In addition, adjustment challenges encountered by people with an HIV diagnosis changed from those related to preparing for the end of life to those resulting from living with a chronic condition.

Objectives: This research aims to explore the impact of biological, psychological and social changes related to the introduction of HAART on the lives of gay men who received a HIV positive diagnosis prior to 1996.

Methods: This research employs a qualitative method. Participants are 6 gay men aged between 40 and 60 who were diagnosed with HIV before the introduction of HAART. An open ended interview using Interpretative Phenomenological Analysis (IPA) methodology was conducted with each participant to explore their experience of living with HIV. All participants were then invited to attend a focus group to discuss the researchers' preliminary findings.

Data analysis: Audio-recordings of the unstructured qualitative interviews on the individual's experiences were transcribed verbatim and analysed using IPA methodology and utilizing NVIVO 7 software. Emerging themes from the whole group will be presented and discussed.

Implications: Investigating gay men's experience of living with HIV long term is fundamental in enhancing our understanding of the psychosocial challenges faced by these men and how their experience of living with HIV may have been affected by or changed following the availability of HAART. This could have potential applications in terms of the tailoring of services to reflect these needs.

1 INTRODUCTION

1.1 BACKGROUND

HIV is a medical condition caused by infection with the human immunodeficiency virus. Soon after initial infection some people experience a sero-conversion illness which presents with flu-like symptoms, but following this most people do not experience any major physical symptoms and may be unaware that they are infected. If left untreated however, people with HIV infection will develop what are referred to as "AIDS Defining Illnesses[1]" which will ultimately lead to the loss of life. There is a wide variation in the time it may take an individual to develop these symptoms. The clinical effects of HIV are due to the breakdown of the immune system, with a reduction in the number of infection fighting cells (CD4 cells) and T lymphocytes (Gupta & Durham, 2007), this would also occur with an increase in the amount of the virus present in the blood (known as viral load). In the United States an individual is considered to have AIDS (Acquired Immune Deficiency Syndrome) when their CD4 count reaches 200 or below.

HIV was previously considered to be a fatal disease but following the introduction of Highly Active AntiRetroviral Therapy (HAART) in 1996, the number of people dying every year in the UK radically declined but remained stable with approximately 500 people dying per year due to HIV (Weatherburn Keogh, Dodds, Hickson. & Henderson, 2007). HAART can lead to individuals achieving an undetectable viral load and sustaining a CD4 count above 200. HIV is therefore now classified as a chronic illness (Siegal & Lekas, 2002).

[1] These include pneumonia, kaposi's sarcoma, swollen lymph nodes, tuberculosis and wasting syndrome.

1.2 HISTORY

The participants of this study were all gay men who had lived with HIV for at least 12 years. In order to appreciate the context of their experience it is important to understand the socio-political background to homosexuality and the beginning of the HIV/AIDS pandemic.

1.2.1. Homosexuality

Homosexuality has been a feature of human culture since the dawn of humanity (Buchanan, 2000) but it was not until the 19th century that such acts and relationships were seen as indicative of a type of person with a defined and relatively stable sexual orientation. Homosexuality has been an area of much contemporary research and contentious debate.

Until the 1960's and 70's, homosexuality was largely a very private affair due to it being classified as a criminal offence in the UK (decriminalised in 1967 in UK) and America. This first started to change however around 50 years ago when the Mattachine Society in Los Angeles tried to organise gay men in America. At this time in the UK, the Wolfenden Committee was reviewing the homosexuality laws because attitudes to sex had begun to tighten and homosexual acts, even if conducted in private, could lead to lengthy jail sentences. As many as 1,000 gay men were serving sentences in Britain's prisons every year. These organisations provided the foundations upon which gay men began to become more open and public about their sexuality (Shernoff, 2006). Following the 1969 riots when the police raided 'The Stonewall', a Manhattan gay bar, the Gay Liberation Front was born (Carter, 2004). In 1973, homosexuality was declassified as a mental illness by the American Psychiatric Association. By 1979, following a decade of social upheaval (including woman's liberation and the sexual revolution), gay men had established a visible, distinct culture in urban areas and central to the new, open gay culture was a celebration of sex (Shernoff, 2006). Bathhouses, bars, and discos for

gay men, as well as other places for gay men to meet and have sex, emerged. By the end of the seventies, in "gay friendly" cities (for example, London, San Francisco and New York) there was an abundance of venues gay men could meet for sexual contact. This frequently involved multiple casual partners.

According to Shernoff (2006), "there appeared to be no limit to the erotic possibilities and men had sexual adventures with other men with reckless abandon...the majority of gay men did not worry about permanent, negative consequences of their sexual partying. An entire generation of gay men came out in a gay, subculture that encouraged men to have sex with strangers as casually as they might shake hands with a new acquaintance". Within this gay subculture, for many men, sexual freedom equated with gay liberation. Even today, many gay men equate promiscuity with what it means to be gay (Callen, 1990). This socio-sexual climate which "celebrated" new found sexual freedom provided an "ideal" environment in which HIV could silently and rapidly spread amongst an entire community.

1.2.2 Sexual freedom and HIV/AIDS

The first cases of HIV infection occurred in the mid to late 1970s although at the time the disease was unknown. By 1980 the virus had spread to five continents and in 1981 the first journal article appeared documenting five cases of opportunistic infections found in gay men (Shilts, 1987; Gay Men's Health, 2007). Issues relating to the publication of this article highlighted issues which continued to complicate the progression of research into HIV/AIDS, namely issues around sexual freedom, gay rights and oppression from the 'moral' majority. Indeed, the publishers of the journal in which the first article appeared moved it from page one to page two and removed any reference to homosexuality in the title. Shilts (1987) stated, "don't offend the gays and don't inflame the homophobes. These were the twin horns on which the handling of this epidemic would be torn from the first day of the epidemic".

The virus which caused AIDS was isolated at the Institute Pasteur in France in 1983. America did not want to acknowledge that they did not identify the virus first, and indeed, the American government announced in 1984 that Dr Robert Gallo of the National Cancer Institute had isolated the virus which caused AIDS, and that it was called HTLV-III. It was not for another year that it was found that LAV and HTLV-III were the same virus. In 1985 a blood test for antibodies caused by the virus was developed (Shilts, 1987, Gay Men's Health, 2007).
In America in the early eighties, the political, religious and academic climate meant delays in the acknowledgement of this new virus which cost lives worldwide (Shilts, 1987; Shernoff, 2006).

In 1995 in America, it was announced that AIDS was the leading cause of death among Americans aged 25 to 44. It was estimated that 18 million adults and 1.5 million children had been infected with HIV worldwide, and the Federal Drug Agency approved the first of a potent new family of anti-HIV drugs called protease inhibitors (Gay men's health, 2007).

1.2.3 The British response to AIDS

In 1982, Terrence Higgins was the first person to die of AIDS in the UK and his friends formed the Terrence Higgins Trust (THT). By 1985 despite there only being 108 confirmed cases of AIDS in Britain, UK blood transfusion centres began routine testing of all blood donations, and it was forecast that a million people in Britain would develop AIDS unless current behaviours changed (Vass, 1986). In 1986, the year it was decided that the virus causing AIDS should be called HIV (by the International Committee on the Taxonomy of Viruses; Gay Men's Health, 2007) the first government AIDS public health campaign was launched but it was another year until the initial 'AIDS-don't die of ignorance' campaign. Also in 1987, Lady Diana opened the first AIDS specialist hospital ward and the first drug trial data for AZT looked promising. It was not until 1989 that a second drug (DDL) was made available (Shilts, 1987, Gay Men's Health, 2007).

In 1991, there was the largest uptake of HIV testing when the character Mark Fowler (a character in the BBC soap opera Eastenders) was diagnosed with the HIV virus.

The public health advertising campaign had a positive effect, the incidents of sexually transmitted infection (STI) reduced, demonstrating that safer sex was probably being practised (Shilts, 1987).

1.2.4 The situation in Scotland

The political climate in Scotland (Britain) at the beginning of the AIDS pandemic was similar to that in America (Shilts, 1987). A Conservative government had been in power for a term and had introduced a number of public spending cuts, including in the NHS. Some felt that the Conservative government was primarily interested in gaining support in 'middle England' rather than with minority groups.

In Edinburgh, HIV infection was found to be at high prevalence amongst intravenous (IV) drug users. The response to this by the Pharmaceutical Society was to restrict the sale of needles. In 1982, a surgical supplies shop in Bread Street, who sold needles to the public, closed. In 1982/83 the Police would routinely remove injecting equipment from IV drug users. From 1982-1986 drug dealers would insist on their drug using clients 'shooting-up' on the premises because contaminated equipment could be used as evidence of possession. In 1983, all substitute prescribing was stopped (for example, methadone) for IV drug users (Richardson & Hewitt, 2006).

A research project into a test for HIV being carried out in Edinburgh in 1984 used blood from haemophiliacs and used IV drug users as a control. It was found that 18 haemophiliacs were infected and the control group showed a far higher prevalence than the haemophiliacs (Richardson & Hewitt, 2006).

In 1986, the McClelland report recommended needle exchanges in Scotland, the City Hospital started a methadone programme and the Pharmaceutical Society recommended sale of equipment to intravenous drug users. The epidemic in the

intravenous drug using population in Edinburgh was therefore thought to be largely over by 1987 as those that were at risk of infection through IV drug use had already become infected. Needle exchange schemes were demonstrated to be a highly effective public health intervention in preventing the virus from spreading more widely.

Edinburgh held the unofficial title of the "AIDS capital of Europe" in the 1980's and one of the main fears was that AIDS would enter the heterosexual population.

1.2.5 HIV/AIDS and Stigma

At the beginning of the HIV pandemic many gay men could not comprehend its magnitude. For years they had fought to be free in their sexual expression and it was hard to believe that this sexual freedom could have such negative implications. The virus set the gay liberation movement (indeed sexual liberation) back substantially as sex became highly associated with danger and fear. Gay men began to fear bodily fluids and avoid sexual encounters altogether (Shernoff, 2006). From the moment scientists identified HIV and AIDS, public responses of fear, denial, stigma and discrimination have accompanied it. Discrimination spread rapidly, fuelling anxiety and prejudice towards the groups most affected, that is, gay men in general and those living with HIV or AIDS. HIV and AIDS are therefore as much about social phenomena as they are about biological and medical concerns (Avert, 2007). AIDS was seen by some as a just virus designed to punish immoral, sinful and unnatural behaviour. A significant number of people continue to hold stigmatizing attitudes to those who are living with HIV (Herek, Capitano & Wildaman, 2002).

1.3 PREVALENCE

According to a sex survey carried out in the UK, 4.3% of all Scottish gay men (1912 individuals) are living with HIV (7.3% of all Lothian based gay men) (Vital Statistics, 2007)[2]. Approximately 70% of those living with HIV in Scotland were male, aged between 35-44 (Weatherburn et al, 2007). The number of new infections of HIV are still increasing in Scotland. In Lothian, approximately one new HIV diagnosis in gay men is given each week. About 80% of all domestically acquired HIV infections occur as a consequence of sex between men (Weatherburn et al, 2007) and about half of all Scottish gay men reported having unprotected anal intercourse in the last year (Vital Statistics, 2007, Hickson, Weatherburn, Reid, Jessup & Hammond, 2007). HIV is still an important issue which particularly affects gay men.

1.4 PSYCHOSOCIAL SEQUELAE OF HIV INFECTION

Infection with HIV is associated with psychosocial and neuropsychiatric disorders (Catalan, Klimes, Day, Garrod, Bond & Gallwey, 1992). The psychosocial consequences of HIV have been well documented (Zich & Temoshok, 1987; Catalan et al, 1992; Brashers, Neid, Cardillo, Dobbs, Russel & Haas, 1999; Barroso & Powell-Cope, 2000; Siegal & Lekas, 2002; Flowers & Church, 2006). The term 'psychosocial' refers to any issues which are not generally considered to be covered by medical, physical or biological. They tend to include issues like anxiety and depression (that is, psychological issues) or relationship issues and work problems (that is, social issues).

People living with HIV are more likely to experience a range of mental health problems (NAM, 2005) and are likely to suffer significant psychological distress

[2] This number did not include children aged 14 years and younger, thought to number 35.

(Cohen, Hoffman, Cromwell, Schmeidler, Ebrahim, Carrera et al, 2002). For example, people living with HIV have a higher prevalence of clinical depression (10-15% compared to 2-5% for the general population) (Dilley, Ochitill, Perl & Volberding, 1985; Ciesla & Roberts, 2001), there is an increased prevalence of suicidal ideation and attempts (Carrico, Johnson, Morin, Remien, Charlebois, Steward et al, 2007), anxiety is commonly experienced particularly fear of death (85% compared to 64% in people not living with HIV) (Kalichman & Sikkema, 1994) and bi-polar disorder is more prevalent (Carter, 2005).

Fleishman, Sherbourne, Crystal, Collins, Marshall, Kelly et al (p.421, 2000) stated:

> "HIV infection may involve recurrent noxious symptoms (for example, night sweats, nausea) medical treatment with unpleasant side effects, periods of physical disability, loss of employment, rejection by members of one's social network, hospitalization, impoverishment and premature death. It is therefore not surprising that studies of people with HIV have reported increased levels of anxiety and depression".

As well as the psychological consequences, above, a full range of social and relationships issues have been cited in the literature as a consequence of HIV. For example, sexual dysfunction (Catalan, Meadows & Douzenis, 2000), work and finances (Siegal & Lekas, 2002), social relationships (Brashers et al, 1999) and sexual relationships (Fleishman et al, 2000)

Medical measures of HIV treatment efficacy are frequently prioritised over psychosocial and sociocultural issues (Green & Smith, 2004). A recent study postulated that three-quarters of people with HIV reported poor mental and physical health because their clinical contacts focused on their CD4 count and viral load. They concluded by suggesting that more focus should be on mental well-being, employment advice and combating stigma and discrimination (Harding & Sherr, 2007; Harding & Molloy, 2007)

In a recent study in France, half of the people living with HIV said they had an acceptable (health-related) quality of life and HAART was not able to restore an acceptable (health-related) quality of life in significant portions of this population (Preau, Protopopescu, Spire, Sobel, Dellamonica, Moatti, et al, 2007). Brashers et al (1999) found that psychosocial issues impacted on the quality of life of people with the virus. Therefore it would appear that successful adaptation to living with HIV should not just be based on medical efficacy alone.

1.4.1 Life expectancy

People diagnosed with HIV before 1996 lived in a climate of death and expected to die. Today, however the situation is different. Investigators from Denmark estimated an individual diagnosed with HIV aged 25 could now expect to survive until they were 64, compared to 76 years of age for the HIV-negative control group (Lohse, Hansen, Pedersen, Kronborg, Gerstoft, Sørensen et al, 2007).

1.5 CURRENT ISSUES

1.5.1. The need to continue practising safer sex

Research has indicated that gay men are reporting less attention to safe sex for a variety of complex psychological reasons, including the fact that media messages often promote the idea that [trial] drug treatments are 'the cure' for HIV/AIDS (Dilley, Woods & McFarland, 1997), therefore posing a real threat to the safe sex message. These individuals are often unaware of the impact that the new drug regimes can have. There are severe stressors associated with complicated drug regimes, side effects of the medication, unknown long term efficacy and safety of drugs, and the financial consequences of long-term reliance on the medications. Issues of drug failure and drug resistance complicate the ability to predict sustained response (Brashers et al, 1999).

1.5.2. Criminalisation of HIV transmission

By 2003, seven men had been successfully prosecuted using Section 20 of the 1861 Offences Against the Person Act, with the individuals convicted of grievous bodily harm after 'recklessly' transmitting HIV during unprotected sex (Carter, 2006). The first successful prosecution occurred in Scotland and was apparently unexpected. It was thought unlikely that a prosecution for the reckless transmission of HIV would be brought under English law, indeed, it was thought a "one-off case, brought under a legal system fundamentally different from that of England" (Carter, 2006). The extent to which these cases and the implementation of the legislation was affecting people living with HIV, with issues such as disclosure, is unclear (Flowers & Church, 2006). It has been suggested it might impact on people's willingness to take HIV testing (Bird & Brown, 2001) because people living with HIV have lost confidence in the confidentiality of their medical records (Carter, 2006). Also, the criminal prosecution of HIV transmission has potential to further increase the stigmatisation of an already stigmatised group (Carter, 2006).

1.6 RATIONALE FOR THIS STUDY

There is still no cure for HIV but there are now effective treatments which enable people living with HIV today to expect a near-normal life expectancy. However, what does this actually mean in the light of the potential HIV sequelae highlighted above? There is relatively little written about people living long term with HIV, specifically gay men, the population still seeing the greatest increases in HIV prevalence. With measures of HIV efficacy concentrating on medical measures, could it be assumed that living long term with HIV is a success when the quality of that life is not questioned? Successfully adapting to HAART is not the only predictor of adaptation to HIV as there are also complex psychological sequelae and psychosocial needs which are experienced in everyday life with the virus (Green & Smith, 2004).

This piece of research aims to adopt a psychosocial perspective in examining the experience of gay men who have been living with HIV long term [3]. A phenomenological qualitative method was chosen for this piece for research because it can give a better understanding of, and access to, psychological phenomena as spontaneously lived (Giorgi, 1995). It also assumes a bottom-up process, that is, that phenomena will emerge from an individual's narrative of their own personal experience. Interpretative Phenomenological Analysis was used for this piece of research (see section 2.9 for a full explanation). Green (1993) commented that most of the studies to date had relied upon quantitative data, and stated "there is a need for more qualitative studies to put flesh upon skeletal statistical associations". Brashers et al (1999) stated that work needs to continue in this area to understand the experiences of people living with HIV. Telford, Kralik & Kock (2006) in their research regarding adjustment to illness urged healthcare professionals to listen to the stories people tell. This study is a first step to fill that gap[4].

1.7 AIMS OF THIS RESEARCH

This piece of research aims to develop a deeper understanding of what it was like to live with HIV at a time when there was no cure or treatment for the virus and how that lived experience may have changed following the introduction of effective treatments. It is anticipated that the narratives of the men may make reference to various biopsychosocial experiences of living long term with HIV. These experiences may have implications and ramifications in terms of their current ability to adapt to life with HIV e.g. work, relationships, self-esteem and confidence

[3] Long term for this piece of work is defined as men who were diagnosed before the availability for ART, therefore men who have been living with the virus for 11+ years.

[4] Literature searches have not identified any studies exclusively concerning the experience of people living long-term with HIV. (Search terms: long-term, HIV, living, experience, pre-HAART, pre-ART; searched EMBASE, Medline, PsychINFO, British Nursing Index and EMB Reviews databases, as well as an internet (google) search

2 METHOD/ANALYSIS

2.1 DESIGN

A qualitative methodology was utilised for this research. Data was analysed utilising Interpretative Phenomenological Analysis (IPA) (Smith, 1995, 2003). Throughout this study a reflective diary was kept to record the researcher's thoughts and ideas about the research and its process.

2.2 ETHICAL APPROVAL

Ethical approval was applied for from Lothian Regional Ethics Committee (LREC) in December 2006. In January 2007 provisional approval was granted but a substantial amendment was submitted. Full ethical approval was granted in February 2007 (see Appendix).

The originally proposed study had many potential ethical issues because a group format was initially considered. It was considered that men might have issues about being identified as gay and HIV+ by others due to this format. Participants might have found it problematic talking about sensitive material (for example, sexual behaviour, possible infection of others, death) in front of others. The substantial amendment changed the format to individual interviews with a follow up group to validate the work (see below).

2.3 RECRUITMENT

Whilst waiting for full ethical approval and with provisional approval, I contacted voluntary agencies in Edinburgh who work with people living with HIV (see appendix for full list with contact details). These were SOLAS, Positive Help,

Positive Voice, Gay Men's Health and Healthy Gay Scotland. Four of the agencies placed posters (see Appendix) in their communal meeting areas and approached men they thought might like to be involved. SOLAS had their own research ethics process which I applied for and was granted. The initial response from the voluntary agencies was poor so I met with each of the groups except Gay Men's Health (they did not have contact with anyone they thought would want to be involved in the research). Four men came forward from this method of recruitment.

Once ethical approval had been granted NHS agencies working with people who fulfilled the inclusion criteria (see section 2.3.1 below) were approached. The Community HIV (CHIV) team and the Genito-Urinary Medicine (GUM) clinic were approached. The researcher attended meetings to explain the research and recruitment process. At the GUM department, all males who had been diagnosed with HIV before 1996 were identified. The researcher put an information sheet in each of these files (identified by GUM number only) with a note to the clinician asking them to inform the patient of the study if they identified as being gay. This resulted in one suitable individual being identified. The Regional Infectious Diseases Unit (RIDU) were then approached and two more people were identified. All participants were recruited by June 6th 2007.

Each individual was given a copy of the information sheet and had an opportunity to ask the researcher questions about the research before each interview took place. On the day of the interview each individual was again given an opportunity to ask questions before signing the consent form (see Appendix). It was emphasised throughout that the men could terminate the interview at any time and ask questions at any time.

2.3.1 Inclusion criteria

Participants for this study needed to be gay men who had been living with HIV for at least 11 years. They needed to have a suitable level of English which would

allow for the information sheet to be read and comprehended and informed consent to be given. The men had to be aged over 16 years, not have a learning disability or to have been an intravenous drug user in the past 6 months. Individuals with a psychiatric diagnosis (excluding active psychotic illness) were eligible to take part.

2.4 PARTICIPANTS

To ensure the men's anonymity the guidelines published by Qualitative Health Research (www.ualberta.ca/~qhr/guidelines.htm) were considered. Limited demographic information was obtained from the men and therefore presented[5]. Seven men talked with me about their experience of living long-term with HIV. Age range was 41-56 years (mean 47 years), years diagnosed 12-19 (mean 15.5 years) and all lived in East Central Scotland.

Each participant was given an information sheet from a person known to them (see Appendix) and contact was then made with the researcher. The researcher and the participant discussed the process of the research allowing time for the men to ask questions and arrangements were made for the interview.

2.4.1 Participants' stance[6]

2.4.1.1 Adam

Prior to his HIV diagnosis, Adam had denied his sexuality and was married with two sons. He "came out" as a gay man when he became ill and was diagnosed with AIDS. He was diagnosed with HIV in 1995. He volunteers for an HIV voluntary agency. He was in a relationship at the time of the interview.

[5] All identifiers of the participants involved with this study have been changed, including names, partner's names and place names.
[6] Participants names have been changed

Throughout his interview, Adam was engaged and appeared to talk openly about his experiences. He comprehensively described his own experience of living with HIV. During the initial stages of the interview the narrative felt unemotional although this changed as the interview progressed.

2.4.1.2 Brian

Brian had difficulty accepting his sexuality. He was engaged to a woman, and "came out" as a gay man when he became unwell. He was diagnosed with cancer and HIV on the same day. He talked much more openly about his cancer than his HIV. Indeed, throughout our interview he had difficulty saying the word "HIV" and would refer to 'the virus' or 'being ill'. He volunteered for two HIV voluntary agencies and had a significant investment in the continuation of this role. He was diagnosed with HIV in 1988.

During his interview, Brian talked primarily about other people's experiences rather than his own. Initially it was hypothesised that this might be because he found it easier to talk of other people's experience and avoid his own. However, he appeared keen to demonstrate how difficult it was to live with HIV, therefore, when his own experience did not lend itself to this stance, he employed the narratives of others. He also appeared to have a limited capacity for self-reflection, choosing instead to provide concrete examples in the form of stories. During the interview he appeared to assume the position of advocating for the voluntary agencies and everything we discussed came back to their importance and use.

2.4.1.3 Callum

Callum initially denied his sexuality and was engaged to a woman. He left Scotland and confronted issues around his sexuality. He had been living back in Scotland for the past five years but continued to have thoughts of moving on. He was diagnosed with HIV in 1992. He had cared for his partner who died from AIDS in the early

nineties. He agreed to take part in this study believing that the process of the research might be beneficial to him in some way.

During his interview, Callum was concerned that he was accurate in relaying the exact timing of events. He was often quite hesitant in speech and appeared to give a very open and honest account of his experience. He was keen for the interview not to be solely about HIV because he did not want to feel that he was exclusively defined by the virus.

2.4.1.4 Duncan

Duncan worked for a voluntary HIV agency and was diagnosed with HIV in 1991. He had cared for his partner who died of AIDS.

Duncan gave a very unemotional account of his experiences when he first spoke of them, perhaps demonstrating a practise effect from frequently talking about his experience in a professional capacity. Once this was reflected back to him over the course of the interview he returned to the same topics and a more emotional (real) reflection appeared to be given. Keeping his emotions hidden was probably protective for him. He used humour and defiance through the interview, often at the most difficult points.

2.4.1.5 Euan

Euan agreed to the interview because he wanted to repay medical staff for all the support he had received. He had cared for his first partner who died of AIDS and was diagnosed with HIV himself in 1993. He was in a relationship at the time of the interview.

When Euan entered the room for the interview he was suddenly taken aback when he noticed some of his best friend's artwork on the wall. His best friend had died from AIDS in the early nineties. This appeared to unsettle him a bit and probably set a more emotional tone to the interview.

2.4.1.6 Frank

Frank agreed to the interview because he wanted to repay counselling staff for all the support he had received. He had cared for his partner who died from AIDS in the early nineties. He was diagnosed with HIV in 1992 and he also had another chronic illness. He was in a relationship at the time of the interview.
During his interview, Frank was willing to please and help and appeared to give a full account of his experience. He became angry when he reflected on his current situation, although this dissipated as he continued to talk.

2.4.1.7 Gary

Gary was diagnosed with HIV in 1989 and considered that he was living successfully with the virus. He thought that being involved with the study would be beneficial for him as he rarely talked about his life with HIV.
During the interview he talked a lot about the concrete parts of his life, for example, work and housing. This might not be related to an inability to be reflective but probably because this was easier for him emotionally. He was in denial about his HIV status for a significant amount of time following diagnosis. He did not talk about death at all and was generally positive and forward focused in his narrative.

2.5 INVESTIGATOR'S STANCE

I consider that my stance as a heterosexual woman with limited experience of gay men who have lived long term with HIV added to my non-judgmental, non-assumptive stance which I believe will benefit this research. I have adequate knowledge to be empathetic and share an understanding of the contemporary clinical regime of living with HIV and am aware of the present medical monitoring process. However, I am unaware of the emotional impact and wider experiences men may have had prior to the availability of HIV treatments.

An aspect to my interest in this area is historical as my growing up and becoming sexually aware coincided with the HIV pandemic, so I therefore remember the public health campaigns in the mid 1980's and have only been sexually active within a 'safer sex' public health era.

Historically, Bishop (2005) considered who was best to undertake research in indigenous settings, that is, insiders or outsiders. It was thought that 'insiders' might "undertake research in a more sensitive and responsive manner" but he also pointed out that insiders might be "biased, or that they are too close to the culture to ask critical questions".

As a third year Clinical Psychology Trainee I need to undertake a large scale piece of research in part fulfilment for the academic requirements of the course.

2.6 UNSTRUCTURED INTERVIEW

An unstructured interview was undertaken with each participant. This was between one hour to one hour 45 minutes duration and took place at a voluntary agency (SOLAS or Positive Voice) or the individual's home.

For qualitative research, including Interpretative Phenomenological Analysis (IPA), semi-structured interviews are often utilised but this has disadvantages which arise from the constraints put on the respondent and the situation; it would close off certain theoretical avenues (Smith, Harre & Langenhove, 1995). I therefore chose an unstructured interview utilising an informal welcoming question[7] followed by one question. The question was:

"Could you tell me about your experience of living with HIV?"

[7] The informal welcoming question was: "could you tell me a little bit about yourself?"

The rest of the interview would run from the response to that one question utilising further open-ended questions in order for a full narrative to emerge. Further questions were informed by current literature on qualitative interviewing (Willig, 2001; Smith, 2003). Smith stated, "good interview technique often involved a gentle nudge from the interviewer rather than being too explicit" (p.60). Open-ended follow up questions were used to encourage the participants to give as full a representation of their experience as possible.

2.7 DATA ANALYSIS

Each interview was transcribed verbatim. An idiographic approach to analysis was employed, that is, one transcript was analysed in detail before moving onto the next (Smith, 2003) and each man's transcript was coded in isolation. The researcher familiarised herself with the transcript by reading it several times before embarking on initial coding. Once codes and themes were established for each individual, the transcripts were then considered as a group considering the similarities and differences between the men.

2.7.1 Coding Criteria

A paper and pen approach was utilised for the initial coding which considered the following three criteria (Flowers, 2007). Initial coding was noted in the right hand margin of the transcript.

- Description and Coding

- Focus upon describing what the participant has said, take things at face value
- Highlight key words, events and experiences
- Noteworthy terms, acronyms, assumptions, sound bites and particular words

- Language use

- The way in which content and meaning are conveyed
- Times when language and content are inter-related
- Details of pro-nouns, pauses, laughter, repetition and changes in tone from hesitant to articulate

- Conceptual and interrogative coding
- Interpretation
- Acknowledgement of self with the analytic process

Once the initial coding was completed, emergent themes were identified and a structure of themes and sub-themes derived (Willig, 2001, Smith & Osborn, 2003), these were noted in the left hand margin of the transcript. Once the initial coding and emergent themes were identified NVIVO7 software was utilised to organise the data. (See Appendix Five for an example of a coded transcript).

2.8 WHAT IS INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)?

IPA is an established method in clinical, health and social psychology, which provides a stance and protocol for the analysis of experiential qualitative data (Flowers, Church, Davis, Marriott & Larkin, in preparation). IPA is concerned with trying to understand lived experience and how individuals themselves make sense of their experience. Therefore it is concerned with the meanings those experiences hold for the individual (IPA, 2007). As stated in the introduction, IPA is phenomenological so it is interested in an individual's own experience of an event (a bottom-up process) rather than to impose a frame on it and then assess whether their experience fits (top-down) (Reid, Flowers & Larkin, 2005). IPA also considers that access to the individual's personal world is dependent on their understanding of it as well as the researcher considering the researcher's own stance (see section 2.9 below).

IPA assumes that the participants are experts with regards to their own experiences and can offer researchers an understanding of their thoughts, commitments and feelings. Participants are recruited because of their expertise in the phenomenon being explored. Participants are able to share their expert knowledge, in their own words and in as much detail as possible (Reid et al, 2005; Flowers, 2007).

2.9 WHY IPA WAS CHOSEN AS THE QUALITATIVE METHOD?

An Interpretative Phenomenological Analysis methodology was chosen for the reasons highlighted below:

- This research is interested in individual's experience of living long term with HIV and achieves this by talking to experts (individuals who have lived long term with HIV). An IPA frame therefore fits the research question (Shaw, 2001).

- IPA explicitly recognises the researcher's role within the process of analysis and views it as integral rather than problematic (as is the case with other qualitative approaches). IPA is thus intimately related to the tradition of hermeneutics (Palmer, 1969). The interpretative aspect of IPA is derived from the idea that access to the participant's personal world can only be partial or incomplete because it is reliant on the researcher's conception of it. Therefore, a "double hermeneutic" is implicated, which is "the participants are trying to make sense of their world, the researcher is trying to make sense of the participants tying to make sense of their world" (Smith & Osborn, 2003).

- It is consistent with the literature. A recent series of articles by Flowers & Church (2006) utilised IPA when talking to gay men who were living

with HIV. They looked at current issues (including the criminalisation of HIV transmission), psychosocial needs and relationship issues.

- The intention of this research was not to develop a theory or model that could be generalised to a larger population. IPA is interested in the individual's lived experience, it does not intend to model themes or issues, as is the case with Grounded Theory (Charmez, 2006).

2.10 RELIABILITY AND VALIDITY

A criticism of qualitative methodology is that it is not rigorous and is therefore more 'unscientific' than research using quantitative data (Shaw, 2001). Researchers have addressed this criticism by presenting general guidelines for assessing the quality of qualitative research (Smith, 2003). Yardley (2000) asserted three broad principles to achieve this aim. Each will be presented and linked to the proposed work below:

- Sensitivity to context

"A good qualitative research project should demonstrate a sensitivity to the context in which the study is situated". This can be achieved in a number of different ways, for example, an awareness of existing literature.

The research was conducted considering the evidence base especially with regard to the methodology. The lack of qualitative research in this area has been commented upon, as has the lack of research looking at people's lived experience of HIV (Siegal & Kraus, 1991; Green, 1993; Brashers et al, 1999). Literature searches did not yield any references written exclusively concerning people living long-term with HIV. Qualitative studies have been carried out looking at the

experience of living with HIV but few of these have included participants from the UK. The limited amount of qualitative research that has been conducted in Britain, specifically Scotland, has utilised IPA methodology. The same qualitative method was utilised, in part, to establish greater consistency with other researchers in the field which it is hoped will facilitate the comparison of this research alongside existing published research.

- Commitment, rigour, transparency and coherence

  - Commitment

"Commitment can be tested by the degree of engagement demonstrated...such as through extended experience using the particular qualitative approach or from extensive knowledge of the substantive field".

Although new to qualitative methods, the researcher has experience working with gay men living with HIV and received regular supervision throughout the research process from a supervisor with experience in this field. Considering the researcher's limited experience of qualitative research she kept to the IPA model and the same process for each interview and subsequent transcription and coding as outlined in the literature (Smith, 1995; Willig, 2001; Flowers, 2007)

  - Rigour

"Thoroughness of the study in terms of the appropriateness of the sample to the question in hand and the completeness of the analysis undertaken".

The question being asked concerned the experience gay men had of living long-term with HIV, therefore, the sample used were highly appropriate because they were gay men who had been living for at least 12 years with HIV.

To ensure the completeness of the analysis being undertaken, the researcher and her supervisor independently coded a section of a transcript to ensure reliability.

The researcher also sent all of the men a copy of the themes and sub-themes and they were invited to attend a focus group to discuss the findings. Three men said they would attend, three said they would not attend or were unable and no response was received from the other man; on the day two men participated. One man appeared to find reflecting problematic but from the topics that arose he chose to discuss some and not others which the researcher took to mean some areas were important for him and others were not. Indeed, what he chose to discuss was consistent with his interview. One of the men found reading the list of themes overwhelming because "everything is there and there is so much". The themes the researcher proposed appeared to be accepted by the men and no new topics arose.

The men were also given the opportunity to comment on the findings in written form. No men chose to do this, even after a reminder.

- Transparency and coherence

"Does the research tell us anything important or make a difference".

It is hoped that this piece of research will add to the current evidence base and make a difference, especially considering it is the first known piece of research of its type conducted within this particular client population.

3.0 RESULTS AND ANALYSIS

Each of the men's narratives will be presented below along with their individual emergent themes.

3.1 ADAM

Adam's account was noticeable under the themes diagnosis and stigma, disclosure of sexuality and HIV, health and medication in Scotland and abroad, loss of self and life, living with HIV and support and relationships.

3.1.1 DIAGNOSIS AND STIGMA

Before he was diagnosed with HIV Adam was a married man and a father who had a strong work ethic. He was having safer sex with men but not within longer term relationships.

"At first, I was married and condoms were the things to use".

He started his story talking about his diagnosis and did not talk at any length about life before he became infected with HIV. Adam found out he was living with HIV due to a decline in his physical health.

"I was diagnosed 10 years ago, I obviously caught it before that, but I took ill 10 years ago, really ill. I collapsed at the bus stop ...I was ill for about a month, delirious for a month...one day the doctor came in and said I had full blown AIDS, I could not believe it, I went absolutely ballistic...I must have had an injection to

make me sleep and I woke up, there was a nurse beside me, I said I'd had a terrible dream".

His reaction to his diagnosis was to feel confused, dirty and avoidant of others.

"I was totally confused and mucked up, I felt dirty...don't touch me...I didn't want to see anybody. I thought what am I going to say to my family, I was married with two boys, but I didn't want to see them, friends, nobody".

He was also in denial about his diagnosis,

"I thought this cannot be right, I've always been safe".

Adam was a gay man who, for whatever reason, was unable to disclose his sexuality. Becoming HIV+ prompted him to have to confront to his sexuality and question aspects of his life which initially he was unable to do, choosing to use denial instead.

Adam had felt stigmatized,

"There's still a lot of stigma. I dunnae imagine it now, but at one time I was quite paranoid, I thought he or she knows I've got it. But it doesn't matter anyway, you have to get the strength to say shut up. I think when you have that strength, I could say I've made choices in my life and I'm paying for that. I'm still here, I'm fighting it, but I'm still here."

He also talked about misinformation and ignorance which added to the stigma of HIV,

"There is still that thing about using cups and that, that's rubbish, and can cut you to the quick...people making you feel dirty, sharing cups. I wouldn't use your cup anyway and definitely not your toothbrush. You cannot get it from touching".

He still believes stigma is an issue,

"Stigma is a killer, a big one...there is still stigma there, still whispers and closed doors".

I believe Adam had issues with his sexuality and possibly felt stigma because of it which added to his non-disclosure. He was then diagnosed with a stigmatising illness which appeared to make him feel paranoid that others were whispering about him behind his back. He initially coped with the stigma by avoiding contact with others but over time he has learnt to cope with his HIV and all that comes with it,

"I was walking along the road and there were jokes and that, you know dirty fuckers and that, my friend was so embarrassed. They said about AIDS and that, he said you don't know about that, and I said I've had it for 5 years".

3.1.2 DISCLOSURE OF SEXUALITY AND HIV

Adam disclosed to his immediate family but was more cautious when it came to his extended family and friends, he asks the question, who do you tell, but I believe there was also an extra part to this question, that is, how will they react.

"I had friends from [other parts of Scotland] coming to see me and I thought how did you know I was in here [hospital]. I felt quite privileged at the time that they came to see me but at the same time I knew I didn't want to say anything you know. I thought, well who do you tell?"

He also sought advice about what to say because he was not able to disclose that he had HIV at that time,

"I still had to ask the doctor, what do I say, I am really embarrassed to say. I mean where I live is a small place, where I work is a small place, What do I say, he said just tell them what I told you-that you have an infection of the brain, which was true...so an infection of the brain which you get from being bitten by cats, I thought I cannot say I was bitten by cats, never had a cat in my life".

Adam disclosed to his immediate family about his sexuality and HIV status together. Although he received support from them he advises caution when people seek his advice about disclosure,

> "...you get guys and girls coming in here, and I say to them do you know your family, but do you know your family".

Adam thought he could rely on friends and family for support with anything but he found this was not always the case when he disclosed his HIV status.
He talked about the anxiety and tension of disclosing,

> "Like I was working and when I finished one day I told my partner at my work, work partner. I thought I shouldn't have done that, I shouldn't have done that, I don't trust them now".

Adam came across as an open and honest man who would probably want to disclose his HIV status to others openly and freely but the stigma attached to the diagnosis and his fear of others response made it difficult for him to do so. He also desired support, and probably acceptance, from others and he realised that he would disclose to people but that maybe he needed to take time and care,

> "And I thought well, do I only tell my family what's wrong, but you need support and you have to do it in your own time"

3.1.3. HEALTH AND MEDICATION IN SCOTLAND AND ABROAD

Adam reported a good CD4 count and viral load and talked about his search for the right treatment regime,

> "...the medication I was on was muck so I stayed where I was for a year and then I took ill again. I was taking medication and it wasn't working so I tried another one, then another one...it was like my time had come up, I got this pill and it gave me such a boost".

The first drug he took was AZT. He was unsure of taking this drug because the initial outcome of its trials was poor and it was widely believed in the HIV/AIDS population that AZT was actually killing people. At this time AZT was being administered widely because there was no other treatment and often given too late, that is, to individuals who were going to die. He mistrusted this medication,

> "At that time you had to sign for drugs, and I thought I'm not that doped up here, I'm not going to sign for nothing here, because the drugs could have killed you".

He then changed consultant which appeared to conicide with the advent of HAART and at one point he was taking 80 tablets a day. More recently he has become resistant to more treatment options but remains optimistic about his future,

> "I think you have to give things a try, research drugs and that. Friends and that say what you taking that for, but you got to try...you keep looking for the magic drug you see, every week".

Considering unwanted effects of the medication, for Adam the worst was feeling tired all of the time but not being able to sleep,

> "And I don't sleep. I could go home tonight and be so tired that I drop off to sleep and I wake up and I've only slept minutes".

Generally, Adam spoke very highly, although briefly, of the medical treatment he had received and his opinion of the medical profession was generally positive and collaborative.

> "I said from the start to the consultants I've met, don't hide anything from me, if I'm very ill tell me, and they wouldn't do that any more so. But they're too nice you know, they're too nice. They're just gents, they've just saved my life".

He did not talk specifically about his physical health other than when he was initially ill and diagnosed with HIV. Adam had worked with people who had disability and he then found himself in similar circumstances, he talked about the

incomprehension of his situation and his drive to change it, which was possible a drive to change it or deny it,

> "I just worked with people who were in wheelchairs, I cannae be in one my self...[I] still walked with assistance and that, and eh, they said you might get home, I was so pleased, just for a visit. I tried to get home but I was so sick, so sick, due to the medication"

Adam expressed concern over the drug companies during his interview and the situation of treatment in other countries,

> "In America where people cannot afford medication they take the trial drugs for free and then they get the drugs all of the time because they did the trail. America tests drugs in Africa and people there get to take the drugs because they did the trial. In Africa they don't get the medication, they take trial drugs because it's cheaper...My consultant said the drugs cost pence, the drug companies, make millions and charge too much for it. It's the drug companies who make the money".

Adam felt angry at being diagnosed with HIV and I wonder if an acceptable way of expressing this anger was towards the drug companies and also considering the different responses of countries to HIV.

Adam believed that living with HIV was more psychological for him now probably compared to the more physical presentation when he was first diagnosed,

> "I think it's a mind thing".

He has felt down at times but was adament that he was not depressed,

> "I was at the stage, I wasn't depressed but I was really quite low. But I wasn't depressed because I saw the psychiatrist, I said I am low but I am not depressed. And then I was back in hospital again for a couple of weeks to try to get my strength back up".

Adam has identified that his loss of a role and purpose was negatively effecting his mood.

> "I'm not one for sitting in the house all day, I could crack. If I had to sit in the house all day I might get low".

He recognised that living with HIV affected his mood and this made living with HIV more difficult.

3.1.4. LOSS OF SELF AND LIFE

The most significant losses for Adam after being diagnosed with HIV were of friends and family which would have impacted upon his sense of self. He also talked about loss of life. He was concerned because his son asked if he was going to die. He was about his son's age when his father died and he did not want his son to have to go through this.

> "He [son] was 11 by the way. I lost my dad when I was 12, it was a nightmare, I thought everyone is going to die, I saw my grandparents die".

He has experienced a lot of death due to HIV/AIDS which made him feel sad and angry,

> "I got a call to say [my friend] had died. I was so upset. I was just talking to her the day before. She just died but. I thought oh no this is the start of the week, it's going to start again, there is going to be a spell".

He was so used to people dying I wonder if he was concerned about his own mortality,

> "Two friends died the same day and my aunt died in the same week, one was a best friend. One was ill but the other was fine, I was away on holiday and it

> happened and my aunt as well, 3 people in the same week. One was a best friend, we spoke every day of the week on the phone, a wee gossip, we were right chatty. He was really, really ill and we ended up in [hospital] at the same time for respite, we would go for nights out together and then, I knew him very well, I said I would come and see him when I got back from Spain. He died whilst I was away. That was the worst I've ever had. I still hear his voice yet".

Adam must have felt apprehensive about his own life when people who appeared well died. I wonder if he also felt guilty for not being around when friends and family died. This loss impacted upon him by making him question the worth of emotionally investing in friends when they just die,

> "It is just too hard too depressing, I've lost too any friends, I don't want to lose any more"

Funerals represent death and for Adam I believe this became too much,

> "I went to a funeral and spoke to my friend, I swore at him, I said you, you, you, you've got no right to leave me".

As a result of the emotions evoked from attending funerals he decided not to attend them anymore,

> "I do feel quite sad, then I think I miss them and I get quite annoyed actually. After one I thought I'm not going to go to any more funerals".

After a period of time he started to occasionally attend but with a sense of defiance towards death,

> "I thought I was going to wear his [a friend's] jersey to his funeral, a red jersey. I've still got it yet. I felt close to him with it, I cannot wash it, the red top, people might think I look like a dickhead in it, but I'm proud to wear it. I wear it to funerals now all funerals I go to I wear it even though it is red".

I wonder if he was able to start attending funerals again because he could trust in his own continued life, so funerals were not so much of a representation of his own impending death.

Adam appeared to believe that death was easier for the person who died rather than those who were left behind.

"...once they're gone its fine but it's the family you leave behind".

He is very close to his family, especially his sons, and it would appear that he does not want them to experience life without their father as he had to at a young age.

3.1.5 LIVING WITH HIV

Adam coped initially with his diagnosis by denying it and isolating himself from others,

"I didn't want to see anybody...I've got no friends any more"

He occasionally used alcohol,

"I could just think get a bottle of knock off and neck it and not make it home".

His sense of humour was evident throughout,

"You need to have a laugh, nae fun, brewin, common sense like".

He likes to help people and feel worthwhile, and he realised that without this his mood drops. He volunteered for a charitable agency,

"I've a purpose in life coming here [a voluntary agency to volunteer]".

His voluntary work structured his week which led to a sense of worth,

> "I'm doing something every day of the week, I've a full schedule. I thought I'm getting by, I'm surviving, I've not much money but I'm getting by from week to week, bills are getting paid, I'm keeping well, I meet people, I'm out and about now".

Adam still feels a degree of uncertainty about the future

> "...you don't know how long it'll last".

He also remembers a time when he would not trust in a future,

> "The end of the week was far away, the end of the month was far too long. I would plan at one time but then there were too may hurdles and that so it went back to day to day. It was a block".

Now he appears to trust in a continued life and is confident that he will have a future because he plans for it,

> "Em, just really my confidence for a start, I am much more confident. I mean, last year, I was planning for Christmas in October".

It appears that Adam has accepted his diagnosis and that he will continue to live.

Adam believed that his attitude had helped him to live for so long with HIV,

> "I'm still here, I'm fighting it, but I'm still here."

There was a strong sense that if you do not fight and stay positive you will die.

> "I've lost too many friends, you see people give up".

Also that he was going to live not die, so along with the positive attitude came a determination to live,

"I'll go on forever now...I've decided".

He also acknowledged for others to be able to cope with HIV, they have to become harder and tough also,

"You have to be a hard nut, my partner has had to become a hard nut".

The terms Adam used, 'fight' and 'hard nut', convey the idea that to live with HIV is very difficult and that you cannot be passive in order to continue to live with the virus, you have to actively fight and resist or you will die.

The concept of having to fight and resist HIV may have come from Adam's initial anxiety because of his diagnosis,

"Nervous wreck, hospital at one stage I used to think it's got to be better this time surely. So pensive, you'd almost think just say something, just like come on".

This then changed into anger because of his diagnosis per se but also due to the losses he had experienced as a result of others dying from HIV. He projected this anger on to the BBC because of the portratyal of a fictional character diagnosed with HIV in a soap opera. The character had lived with the virus for a number of years and was then apparently shown to run out of treatment options.

"...this was not a soap this is real and you cannot say something like that. How would I have felt if I had started medication and told there were no more options left".

Even though he has accepted living with HIV to some degree, I believe that Adam still has a degree of doubt about his continued good health and life and his fear of dying is still fairly close to the surface.

After living with HIV for over 12 years Adam realized his fear had gone,

> "...for the first time in the world I realised I wasn't scared any more".

Despite his positive attitude and decision to live, there appeared to be times at funerals when his resolve would be tested and his worthlessness would resurface highlighting the uncertainty which accompanies living with HIV,

> "You can't say sorry for your loss, they want their sisters, brothers, mothers, lovers".

3.1.6 SUPPORT AND RELATIONSHIPS

Although he did not talk overtly about his financial situation, Adam has to cope on a limited income but appears to do very well with this. Despite his initial need to isolate himself, he now prioritises socialisation but emphasizes that it does not have to be costly. This support is very important to him, both giving and receiving.

Initially Adam did not feel supported when he was diagnosed with HIV,

> "...at the time I thought friends would come forward and I was really disappointed".

He then came into contact with the support services and has benefited greatly over time,

> "I've realised I am the same person I'm just a bit stronger. I've had discussions at groups, mixed groups, all groups, and I can say you're a stronger person"

I wonder if Adam would have been able to reach this point without his HIV diagnosis forcing him to disclose his sexuality and therefore enabling him to lead a lifestyle which otherwise may have remained hidden and denied.
His son had also benefited from the support agencies,

> "My son, my eldest son, now he's fine with it because he phoned up [a support agency] and got someone to speak to".

Adam was in a long-term relationship with a man who was married to a woman when he first met him. It appears that he felt he was taking a risk at the start of their relationship and I wonder if he thought why would anyone want to go out with someone living with HIV,

> "I thought there would be a chance and he wanted to make a go of it. He says so lets do it then, even if it breaks Betsy's leg., but he still invited me in".

He mentioned that this inbalance was addressed early on in thier relationship when a friend pointed out to his partner that he (Adam) was more at risk than he was,

> "He [friend] said, look Adams got this not you, that's something as well, we are at risk not you, we cannot afford to catch your coughs and colds...I say to people if your immunity is that low you cannot afford to take risks with others germs".

He feels he has made his partner more sociable and educated him about HIV,

> "...he didn't have any friends, acquaintances and now he's never in. I said to him what's your diary this week, and he'll say you know, we have a laugh. He has so many friends now, he wasn't like that before he met me".

To a certain degree it would appear that he has felt that he has to compensate for his HIV status with his partner.

Adam is able to talk to his partner and feels supported by him,

> "I felt so good having someone to tell. I can talk to him".

Although during the interview he did not talk overtly about the physical side of their relationship he did note that they practised safer sex and his partner is occasionally tested for HIV. It would appear that although not an overt problem in their relationship they both consider HIV within their relationship.

3.1.7 SUMMARY

Adam 's whole life was turned around when he became HIV + not simply because of the diagnosis but this confirmed that he was a gay man leading a heterosexual life. As a result of his diagnosis he had to disclose not only his status but his sexual orientation and because of his disclosure he lost some friends.

Receiving the diagnosis and the ensuing journey appears to have markedly changed Adam's personality and attitude to life, he has learnt to be assertive, indeed he stated he is stronger due to HIV.

Adam appeared to be very positive in outlook but he also acknowledged that the diagnosis came with a cost. This does not mean that living with HIV has been easy for him, when initially diagnosed he said he felt dirty and unsupported. He also expressed that living with the virus was difficult especially as he apparently is coming to the end of treatment options as he develops resistance to more of them. He maintained that he lived a full life and was keen to highlight that he was more than just his HIV diagnosis. Adam talked a lot about his family, particularly his relationship with his oldest son. He was also keen to point out that being HIV+ does not make you a second-class citizen which highlights the stigma felt when receiving the diagnosis and living with the virus.

Adam was very angry at the drug companies and he talked about the plight of others living with HIV (that is, people living with HIV in Africa) who did not have any, or as many, treatment options. I believe he likes to help others and he maybe feels powerless to do this for people who are living with HIV in other countries, leading to feelings of anger.

Adam coped with living with HIV and the journey he has been on emotionally, socially and physically, including a positive attitude. He is in a relationship and he talked about issues relating to this including the support he receives and gives to his partner. He was very keen to advocate for support services and the realisation that he might not be able to receive the support he desired from family and friends he had before he sero-converted. He has experienced a great deal of death since living with HIV which he initially coped with by avoiding and now be appears to use defiance. He has had few physical and mental health problems and he reported a good relationship with his medical health providers.

3.2 BRIAN

Brian's narrative could be encompassed by the themes of diagnosis and support, health and medication, being diagnosed with HIV means death, fear and coping with HIV and HIV support services and relationships.

3.2.1 DIAGNOSIS AND SUPPORT

Brian had a trade but also worked in entertainment. He was in denial about his sexuality and had a relationship with a woman.

> "...well the crazy thing about it was I tried to prove to myself that I wasn't gay, which of course was ridiculous, I stupidly got engaged, em, to a woman that is".

He found out he was living with HIV due to a change in his physical health,

> "Someone at one of the shows turned up with photographs and I had a side on view, and it looked as if half a tennis ball was sticking out of my neck. I went to the doctor and was told it's over work, it's over work, it's over work...I just kept going back saying it's not going away, and this carried on for about 9 months. Then on the same day I was told I had non-Hodgkin's lymphoma as well as HIV".

He believed alcohol was involved when he became infected.

> "...me, personally, I was drunk...so the chances are that's how I got the virus, through stupidity and down right ignorance and being totally plastered".

Initially Brian did not have any reaction to his diagnosis but this might be because it was overwhelming receiving a diagnosis of cancer and HIV considering he was a young man.

He talked about the emotional environment into which some men were diagnosed as a result of the media coverage of HIV/AIDS,

> "When they first advertised it on the television saying 'don't die of ignorance', and this was how they advertised it, you know if you caught the virus it was through your own ignorance. Maybe sometimes it was ignorance but if someone was raped, for example, that was not ignorance".

After Brian had received his HIV diagnosis he sought out his best friend to share the news with and was devastated with his friends' response,

> "...when I told him that I was positive he never phoned, he never came back to the flat, he never had any contact with me whatsoever, he never even enquired about my health whatsoever...I left the house, I got into the car, and I drove down the road and I stopped. I was physically shaking and I looked in the mirror and he came out of his mother's kitchen, and the cup that I had been drinking out of, he smashed it against the wall, picked the pieces up and put it in the bucket. I burst into tears and at that point I decided I was not going to tell anyone"

As a result Brian would disclose that he had cancer rather than HIV and he became more selective over who he disclosed to. Indeed, he did not disclose his HIV status to his family initially. When he did it was a more positive experience and he was able to receive some of the support he desired.

> "I consequently told everybody else, and fortunately for me, my, I've a very big family, my mother is the eldest of 8, em, and between my dad, he was the youngest of 3, so between both my parents I have 44 cousins, so it's a big family, and none of them have said anything derogatory".

He did not comprehend how serious his diagnosis was until he started to disclose to people and the brevity of their response made him realise how serious it was,

"I don't think I registered that it was terminal illness until I started to tell people and got the response from people".

Brian disclosed his sexuality at the same time as he disclosed his HIV status.

"...and again when I first told my father, the first thing he did was went for the whisky bottle...he poured himself a drink, then he poured himself another drink and then he poured my mother a drink, and then I went and poured myself a drink...and we just kind of sat and looked at each other for about 5 minutes no one actually said anything".

When his father did speak he was supportive and Brain remembered always being supported by both of his parents in relation to both his sexuality and HIV status. From his experience working in HIV support service, he believed that parents had more of an issue accepting their sons' sexuality rather than their HIV status.

"They took it upon themselves, were they to blame type of thing, and they wouldn't have come in here [support center], they didn't want to believe it, that their sons were gay. That seemed to be more of a problem than the fact that they had the virus. I know that sounds crazy...but the fact that they were gay, that seemed to be more embarrassing".

The reaction Brian received from his best friend highlighted the stigma, ignorance and fear that was commonly felt regarding HIV/AIDS at that time. He did not explicitly talk about stigma he felt or had experienced as a result of his HIV status but he did comment upon attitudes towards sexuality,

"I mean there is enough prejudice out there now, let alone when I was at school, which wasn't exactly yesterday".

He believes the attitude of the general population regarding sexuality has changed compared to when he was first diagnosed, and first came out, in 1988.

"Things have changed a lot as far as, as far as the being gay situation is concerned. A lot of things have changed over the past 20 years and people will just accept someone. It's like the old Les Dawson thing, they would whisper. I, you know, he's gay (whispered) or she's sleeping with (whisper), which is nonsense, ridiculous. Whereas now, you can openly say gay and no one thinks, oh, how terrible to use a word like that".

He was in denial of his sexuality when he became infected with HIV and over the years has accepted it, the above comment therefore probably reflects Brian's move from denial to acceptance regarding his sexual orientation, possibly his HIV status as well.

3.2.2. HEALTH AND MEDICATION

When Brian first became ill it took several months until he received a diagnosis of HIV, and cancer, and he then underwent years of treatment for his cancer without reference to his HIV.

"Two years later [after initial treatment for cancer] the lumps came back again and I had to get radiotherapy treatment and then I went back to work. 3 years after that, it came back again and I had the chemotherapy treatment, 8 months of it, which nearly killed me. I mean they stopped and started and stopped and started".

He also had other physical health problems as well as HIV and cancer,

"I've also got [glandular] trouble as well as [a neurological condition], that's just to complicate the situation, I've had [the neurological condition] since I was 18 but em, it doesn't really, it's another problem"

Brian has been taking HAART since 2000,

"It means a lot to me because I am keeping well and the medication is working. People who didn't take the medication before and refused to take it, for whatever reason, some of whom are no longer here, um, which is unfortunate, but everyone has choice...but by the same token, a lot of people had a lot of terrible reactions to the medication. Fortunate for me that has not happened, but this is still my first".

He appeared to make the transition on to medication well and mentioned few side effects,

"Obviously there are times when you feel unwell and you just feel that you want to stay in bed all day, and that does unfortunately happen every now and again, but fortunately for me, it does not happen too often and long may that continue".

Polypharmacy was an issue,

"I personally found it very difficult because of the other medications I am taking...it causes some kind of problem in the stomach that causes you to keep throwing up even though there is nothing in your stomach, you still want to be sick and it causes gross pain. Consequently you cannot even take pain killers because you know they'll come up as well, you cannot take anything until everything settles back down again. Because of something like that, it is a constant reminder that you have to take the medication on a regular basis and you stick to that".

It is interesting that he minimizes his discomfort but this might be because he compares him self to others who have had a worse experience,

"Well the medication causes problems because it does cause terrible effects and you can feel ill. But the reaction from that is that it lasts for days and days and days and days and days, it can go on and on and on, and it's not just something that can last a couple of days, it can last for weeks".

Brain also talked about immunity and resistance to the medication,

"Because the medication, the combination therapy, lasts for however many years you know, well the doctors tell you from the start, you will eventually become immune to them, so you will have to change your combination therapy, the tablets, you'll have to go through it again and again. It's like going back to the beginning again. Also that combination that their going to give you might not work for you,

> and so you have to go for another one, or another one, or what inevitably will happen is you'll get with drawls from one and reactions to the other one and you have to go through that period of going through the reaction to the other drug and with drawls from the other and you don't know which one is what. Which one is the reaction or which ones the with drawl"

I wonder if he called upon the experience of others so I would not be given the impression that living with HIV was in some way easy, which may have been conveyed given his experience alone. Or maybe he was expressing his fear that so far his experience of taking medication had been relatively unproblematic but he worried in case he developed resistance and/or had to change his regime.

Brian talked about a fantasy he had for curing many diseases including HIV,

> "...that's when I wish I was H. G. Wells and had a time machine...I would turn it forward and get the cure for many, many diseases, one of them being cancer, to bring my dad back, and second HIV, as well as many others, and then turn it back".

Although he stated this fantasy in a jovial manner, I believe he would like to live without HIV and he sees no way that is going to be achieved in his lifetime so involves fantasy.

Brian had concerns over the medication that people living with HIV have to take and the potential implications of this for people longer term,

> "...but it is the long term effects of the tablets that concern me, that's what the problem is. People don't so much die of AIDS now, they die of liver failure and stomach related problems and so on and so forth. People often drink a lot which causes problems with the pancreas and, but again, I cannot complain since I've lived all of these years. And hope to live a lot longer".

I wonder if these are concerns he has for himself, that is, he will not die from HIV but instead due to a side effect of taking potent medication long term.

Brian talked about mental health consequences of living with HIV, specifically depression and increased incidents of suicide but did not talk about either with regard to himself,

> "It's (HIV) not something I get depressed about because it's, I've got the virus and dealing with it, living with it and I've lived a considerable amount of years, far more so than many, many more people. And I've seen a lot of things happen over the past 20 years, from people who have not been able to cope and had the unfortunate situation of rejection from family and friends, and that has caused them to commit suicide, in many, many different ways, some of them horrendous".

He talked about people using support services more and contemplating suicide more pre-HAART because they were scared of dying.

> "Suicide, you have to be, as far as I am concerned, you have to be extremely brave. I mean I couldn't throw myself from, in front of a train, or jump off something high or take a knife, a sharp knife to my wrists. I mean you have to be extremely, well mentally disturbed, or extremely brave to do either and I don't have the bottle to do it, I'm not brave enough...it is also extremely important as far as support centres like this, as far as these places are concerned. That these places continue getting funding and finances even though they are not being used as much as they were years ago".

Brian appears to keep mentally well by believing in his future and maintaining a positive attitude towards life,

3.2.3. BEING DIAGNOSED WITH HIV MEANS DEATH

Brain did not talk about loss a great deal. Considering he likes to maintain a positive attitude and forward focus, I wonder if he chooses to detach himself from the loss and death he would have seen and experienced given the number of years he has lived with the virus.

He did mention that being diagnosed with HIV meant you were going to die,

"Once you had HIV that was it, you were labelled, you know, you know, you were on your way to the closest crematorium, book your space type thing".

This was the expectation when he was diagnosed and it was also his lived experience

"...before medication, the combination therapy, people were dropping like flies".

3.2.4 FEAR AND COPING WITH HIV

When Brian was first diagnosed with HIV he found the diagnosis of cancer easier to disclose to people and cope with, so he denied his HIV. During his interview he rarely used the term 'HIV' which made me wonder if he has completely accepted the diagnosis today or has just got used to not talking about it.

His initial experiences of disclosure led to him adopting a fighting attitude towards HIV and made him realise he wanted to live,

"That's how I've always been since that guy smashed that cup against that wall. It made me, although I burst into tears, it made me stronger because it made me think right you bastard I'm going to win...after talking to my parents and everyone else, I thought I'm going to fight this all the way, and that's exactly what I've done"..

It appears that Brian likes to contribute and keep busy which can be difficult because he acknowledges that he has never returned to how he was before diagnosis. He volunteers for two charitable agencies and appears to enjoy giving back something to a community which has given him so much.

"However, I pulled through and, but, I never really, my hair never really grew back and never really had the, I lost a lot of strength as well, but it wasn't as if I

was going to give up. I still wanted to do something which is why I came in here and volunteered...it's not as if I'm sat about the house all day doing nothing"

Brain believes there is still a lot of fear in the gay community about HIV and this contributes to people not getting tested. Throughout his interview he advocated for HIV testing and the need for more people to be supported to be tested.

"They haven't been tested and I do in fact ask people if they have been tested...but I say I was in the same situation as you, I was well for many, many years... so anybody can have it...fear, absolutely fear, they don't go out and get tested because they are frightened of the results. They are frightened of the rejection it causes, they wouldn't know how to cope with the situation".

I wonder if this is how he felt when he was diagnosed and, indeed, if he might have felt fearful of HIV prior to diagnosis and dealt with it through avoidance. Through this experience, it would appear that he is trying to prevent others from making the same mistake he did which led to his sero-conversion.

3.2.5 HIV SUPPORT SERVICES AND RELATIONSHIPS

After his diagnosis Brain was able to keep working despite undergoing treatment for his cancer on and off for a number of years. He still remains active and involved through his volunteering. He acknowledged that he would not be able to work now because of fatigue,

"I couldn't do a 40 hour week because I would be exhausted, that is one of the unfortunate things that's when you realise, when it kicks in that there is something wrong with you. You might feel after a day or two that you are ok, but I couldn't do a 40 hour week, I've tried it and I felt absolutely shattered, Monday to Friday I am shattered and even over the weekend; come the Monday I am still shattered".

Brain is a very keen advocate for the support services. He has experienced support from them directly and for his family members, he has also seen what others have gained and continue to benefit from them.

> "Prior to the treatment, people only lasted 6 months maybe a year and they were coming in here [voluntary support centre] because they were frightened, it was total fear. And there was, there would be hundreds of people coming through the door. And support centres are important because if someone was, had, just been diagnosed at the hospital they get a whole load of leaflets, information and leaflets and then sent away and then where do they go...they'll either go to the pub, or get a bottle and sit at home and get drunk in the house which can cause inevitable problems. Whereas the support centers, they can come along and talk to people".

He talked about practical support as well as emotional support or the need to just be in a non-judgemental place,

> "That's why places like [a support agency] are so, so important, so if you needed something you could phone up, like food for instance, if you needed food or something from the chemist, you could phone up and people would come because if you, if for instance, if you've decided not to tell anyone about the disease because of the response it gets, then you're limited."

He talked in particular about the welcoming environment in one agency,

> "Many, many, many people commented on, how you can walk through the door and it isn't like a reception, office type building, it's just like a living room and it's welcoming. I for one have always supported that look...people can come in and stay in touch".

Not being judged and feeling welcomed would appear important to Brian and they are the opposite of how he must have felt when he initially disclosed his HIV status.

He had also gained a secondary benefit from the support agencies because his mother had accessed them,

"The reason why support centres are so important so you can bring people in and make them feel at ease, especially family members and, well for me, my own parents".

He noted that his mother still used one particular support centre which was a comfort to him especially when he considered that his father was no longer alive and he considered his own death.

"...but if that were the case then she would get the support by coming in here and she also has several phone numbers of my friends who are positive ... just other people who are positive who I have met over the years, who she would be able to phone for support".

Brain is worried about the future of the support services especially considering that people diagnosed with HIV now do not appear to have their lives as disrupted by the diagnosis and are able to continue working,

"People don't realise just how important they are, even though the places aren't packed the way they used to be all with people who are positive, but there still there should people need them and that is another reason for why places are so important and the funding continues".

Brain talked about a specific project one of the agencies had set up that involved people living with HIV going into schools to talk about their experience. He advocated younger people hearing about how living with HIV affected your life even though there are successful treatment options, he also acknowledged how controversial this project was,

"I know there have been people involved with going into, talking to school kids, in here and they did get some kind of response from it, but again, it's going into dangerous grounds, going into schools as far as the catholic faith is concerned, I mean their religious beliefs and so on and so forth, and that is quite dangerous to get involved in that. So it was a catch 22 situation, you're telling kids one thing but it is illegal for them to have sex but then by the same token they're still going

to do it. I mean kids smoke, they shouldn't buy fags in shops but you see kids smoking".

I think Brian sums up here one of the problems that HIV has faced from the beginning of the HIV/AIDS pandemic because it is primarily spread though sexual activity and advising people what to do sexually leads to problems because of religion, age, human rights etc. It would appear that these issues will never leave HIV.

Brian had experienced different responses when he had disclosed his status to a potential new partner and had decided to be very open about his status and use more creative ways to find boyfriends,

"What I've been doing recently is advertising in the things like the Scots Gay magazine and Positive Nation magazine for a partner because I always tell people. I know I could go on the gay scene and pubs and that but I cannot be bothered. But I'd been going into pubs and meeting people and telling people. If it looks like sex is on the agenda I would tell them right away I was positive, letting them know. But then if you turned away and you turned back the chances are the fire exit door is swinging and their drink is left at the bar. Because they've run away and it's called fear, and the crazy thing about it is if you asked them if they had been tested, 99% of the time the answer would be no".

I believe this proactive, open stance that he has adopted highlights how society, as well as Brian, have accepted HIV. It is now acknowledged as an illness which is not going to go away, which people can live with for longer periods of time and, so, needs to be accommodated, for example, in specific HIV+ literature.

3.2.6 SUMMARY

Brian initially did not experience his diagnosis of HIV as problematic although he was not prepared for the diagnosis. Prior to living with HIV he had not disclosed his sexuality and had relationships with woman. He was anxious about disclosing

his sexuality and HIV status to his family, especially his father. His family did support him and he believes this helped him to maintain a positive attitude which has helped him be able to live with HIV. It would appear that disclosing and subsequent acceptance of his sexuality was more of an issue than his HIV status, indeed he believes sexuality is still more of an issue for some than HIV.

During his interview Brian often gave the experience of others if his experience did not lend itself to the point he was making or instead of his own experience. This might highlight how difficult he has found living with HIV although he feels his experience alone is not enough. It may also demonstrate his fears for others having to live through what he has experienced. It was interesting that he did talk a little about the losses he had experienced whilst living with HIV, however, he did stress how difficult it is for him to live with the virus, especially given his additional health needs. He also acknowledged the stigma of living with the virus and what life was like before he was diagnosed with HIV.

Brian talked about the change in importance of HIV post-HAART. He believed that because there is now effective treatment for HIV it is not seen as important, therefore, by extraction, he was possibly suggesting that people living with HIV are also not as important. This led to him wondering about where information about HIV will come from for young people who are becoming sexually active. He also advocates that everyone should be tested and that people do not get tested because they fear a positive result.

Brain has benefited greatly from the support agencies both directly and indirectly. He is concerned for this continuation, especially given the advent of HAART.

3.3 CALLUM

Callum's narrative could be covered by the themes of life before HIV, diagnosis and stigma, physical health and depression, loss of self, tangible loss and death, coping with HIV and work, housing and relationships.

3.3.1 LIFE BEFORE HIV

Callum is one of the oldest in a large family and his father died when he was still a child,

> "I tended to help my mother look after the kids when my dad died. I would help feed them, dress them, wash them and get them off to school and then get myself off to school. So I was the one doing all of that for the ones younger than me."

As he got older he felt he needed to be away from his family so he left Scotland for another country,

> "I wanted to get as far away as possible from my family, I'd say that was the main reason and partly, because even then I was not aware of my sexuality and I didn't accept my sexuality until I was 27".

When he moved he started to realise things about himself,

> "Um, I initially trained as a printer with [a Scottish] University, a manuscript restorer, and I continued, I finished that training in [the other country]. Then I felt it was not for me, being hidden away in the bowels of a library every day, I liked to be with people, so I took a job as an auxiliary nurse on one of my trips back to [Scotland]".

He was in denial of his sexuality for a number of years and had a long term relationship with a woman.

"Up until then, I had one girlfriend for several years, we lived together".

Callum fondly remembered his life living abroad,

"I just know I didn't seem to have any problems, I know I lived in a nice house, money wasn't a problem, I had a good job, I was earning good money and yeah, it was privileged"

Soon after leaving Scotland Callum met a man and after a period of time they started a relationship, this was the first time he had expressed his sexuality and been aware of HIV/AIDS,

"Um, not long after I arrived in [another country] in 1985 I met [a man] who, who became my partner, and not long after I met him I suspected he might be positive but he would not have tests".

His partner's denial of his HIV status continued until he was very ill, he then went to the doctors and he was diagnosed with AIDS without having a blood test,

"He totally, he buried his head in the sand, he did not want to know until he got to the point that he. I was with him when he went to see this specialist about this problem that was going on. They didn't even check his blood and the first thing they said was well you've got AIDS, but I'll take some blood today, and he died not long after that, and I'm talking about, about 1991".

3.3.2 DIAGNOSIS ANS STIGMA

Callum nursed his partner until his death, he then chose to have a test which came back positive for HIV,

"Just a few months after [my partner] died, I thought I am going to get tested, I don't want to do what [my partner] did, I want to know now, I don't want to go through what he went through."

Initially after his diagnosis he thought he too would die quickly,

"When I was told, Callum you're HIV positive, I thought 6 months I'll be dead".

I believe Callum did not agree with the choices his partner made with his HIV and this directly impacted upon how he approached his own HIV, that is, instead of being in denial of it, he actively chose to get tested and to take treatment. It is interesting that he was unable to do this when he partner was alive though. It would appear that he had to wait until his partner died because his course of action might in some way have been perceived as being disrespectful to his partner's choices.

His reaction to his diagnosis appeared to show a level of acceptance because he reacted to it and sought treatment, but Callum still harboured thoughts of one day stopping his medication because he did not need it anymore. I wonder if it took a number of years for him to accept his diagnosis on an emotional level even though he appeared to accept it at more of an intellectual level initially.

"...and I still think there is going to be an ending to this but I know I'm fooling myself. This was really bad [when I lived abroad], it's actually not as bad now as it was, but I had this stupid idea that after so long I would be able to stop taking the pills. I don't know who I was trying to fool, well I was trying to fool myself".

Callum disclosed to his family about his HIV status and sexuality together

"I sat and wrote almost identical letters, well not identical...so I actually said [about my sexuality] and then added, oh and by the way I'm HIV positive as well".

His family were not supportive, his mother kept in contact but apart from a comment in the first letter, his sexuality and HIV status were never spoken about,

> "...my mother, well she said it was unnatural and all of that stuff"

He has always been discrete about his HIV status because of the stigma attached to the diagnosis,

> "I mean I don't like hiding it but I don't go about shouting it from the roof tops because you've got to be careful, you know what I mean because there is a huge stigma attached to it".

Indeed, one of the only areas of his life in which he considers himself to lack in confidence is concerning disclosure and he often uses avoidance to cope with this,

> "...but I think inwardly I am [a confident person], it is only with issues around HIV that I am not, like disclosure it creates a lot of tension and anxiety when I get to that point when I think oh I've got to tell someone, so I avoid situations like that".

Callum has noted that disclosing was not such a problem when he lived outside of Scotland,

> "In [a city in another country] if I even told anyone I met I was positive I was never a problem, they were kind of cool about it. Not that I told many after [my partner] died, but I did meet a few and told them of course and it was never a problem for them. But in [Scotland] I've not been in that situation where I've felt I should tell that person".

He discloses his status primarily if he thinks that sex or intimacy is a possibility but also notes that this situation has not occurrred often. I wonder how big an impact his denial of his sexuality before HIV would have on his sexual behaviour, it is is easier to life without sex because it was a side of himself he never fully integrated before HIV made it more problematic.

Callum has had problems with verbal and physical abuse which led to him having to be re-housed and without a car,

> "I had a lot of problems with harassment both verbal and physical, and eventually, after over 3 years, I had to get re-housed".

He does not know if this was related to his HIV status or sexuality.

His relationship with his family has always been distant and the family do not enquire about his health,

> "They've [family] known from day one that I am positive but they have never ever, to this day, said Callum how is you with the HIV".

It swould appear that stigma plays a part in their avoidance of their siblings HIV.

3.3.3. PHYSICAL HEALTH AND DEPRESSION

Callum was diagnosed with HIV in 1991 and expected to die within 6 months of his diagnosis because that was his experience with his partner and with others in the city in which he was living. He appeared a little surprised that he had not died and indeed stayed well,

> "I don't know how I've stayed healthy for this long, I've no idea".

He commenced treatment when he was diagnosed with HIV and stated that his treatment was good because he was not having many medication side effects, but this has not always been the case,

"There have been some, there have been some medications I've been on which have been a nightmare...the thing is I would not stop taking them, I would persevere. So for one time I was on this medication which caused a severe, terrible diahorrea, but I persevered, and persevered, so that after nearly a year I said we need to change this and we did. Certain medications I've had to stop because of whatever the side effect was but I never gave up with them straight away, I always gave them 6 months, at least 6 months of suffering. One of them made me really manic, it made me as high as kite, I had all this energy and I thought good I have all this energy but I knew it was, mentally it was not right".

It would appear that for Callum side effects of the medication are part of what he has to cope with in order to live with HIV, so as long as his CD4 count and viral load are good he will put up with the consequences of the medication. He commented upon the fact that twice a day he is reminded he has HIV, almost as if he wants to forget it but is not able to,

"Twice a day you are reminded of it, you know, take your pills and all that".

Before returning to Scotland Callum received a diagnosis of a chronic condition which he believed was due to years of HAART.

"I was diagnosed with [a chronic illness] just before I left [abroad], the immunologist did not think it was in any way connected to the HIV but I don't believe him, I think it is and I think it is possibly connected to the medication I've been on since 1991"

Callum also takes anti-depressant medication along with his HAART,

"Well I think I've been on a huge, the doctors have tried me on every anti-depressant there is under the sun. I'm on one just now that I have no side effects at all with, I don't know if it is helping at all. It is difficult with anti-depressants to know. I've been on this one for over a year, I take it and. Some days I still get, I still get depressed though, so it's hard to know. I've thought a few times I might stop it and see how I am".

He thinks his anti-depressant medication is working though because he is now able to plan for the future,

> "The other thing is, actually, I think what makes me think the anti-depressants are working is before I would not plan anything, now I will plan. Last December I planned, booked and paid for a trip in May, now I would never have done that, I wouldn't have planned for next week, let alone 5 months down the track".

It is interesting that Callum considers his ability to consider his future is down to medication. He has a medical background and appears to think in a medicalised frame.

Given Callum's medical background he stated that he sometimes took matters into his own hands and made his own treatment decisions, and maybe that sense of autonomy, or control, is one of the characteristics that has kept him alive.

> "I make decisions about medication and just do it and I don't tell anyone, I'm a law unto myself, the doctors get frustrated".

The biggest hurdle for Callum living with HIV has been depression,

> "The depression that has come along with it or has come along with it because it effects your whole being, it paralyses you, well it paralyses me, I feel paralysed. When I'm in a real depression, dark, I'm paralysed and that's when all thoughts of suicide, I hate that word suicide, I would rather say ending it all, it sounds better. All these dark thoughts come into my head and it's almost a comfort having these thoughts because I think doing that would be a release and I know I have an option. I have a choice, it's like an insurance policy, well, if things get too tough, I know I can do that and it is almost a comfort to me to do, I could do that if things get really bad"

Although the suicide paralyses Callum he has also seen a positive in it because he views the suicidal ideation as a positive, it gives him the option of death if things get too bad.

In the past he has considered suicide and told his family about his choice,

"I know a lot of it was, because I told everybody, it was a cry for help. I didn't want, I couldn't do it without telling people, I'd hate to think people didn't know I felt that way. So I decided to tell them all that I've thought of these things, so if I were to do it they wouldn't be surprised, they would be oh he did tell us, it wouldn't be a shock. I was kind of in a way preparing them for what I thought I might do, but I didn't do...my 3 dogs [stopped him from attmepting suicide] and I think, and also, the not knowing what happens when you do die".

The option and choice of suicide is real for Callum and it would appear he has considered using it, I wonder if the reaction of his family when he told them he was going to kill himself was also another reason for him not attempting it because they appeared to react and not want him to end his life, even if they did not show it in daily life and expressed it an annoyance.

Callum's self esteem has also been affected by his HIV diagnosis,

"It does affect your self esteem, I know mine".

Talking helps him to cope with the mental effects he has experienced whilst living with HIV,

"And I think talking about it does help, I certainly don't, I don't talk like this all of the time, I couldn't do it all of the time".

He had received treatment for his mental health problems in the form of talking therapy (as well as the medication mentioned above),

"Well now that [my brother] has gone there is no one I can go to, although I do have a counsellor who I can see when ever I want, but it is different. You get to a point you think I can ramble on saying I'm feeling this way and that way but at the end of the day you're not feeling any better. So one day I said I don't want to see you anymore. I think that lasted about 3 months and then, and now I do now occasionally say can I see you. I think what I need is more diversion to get out, to stop myself from thinking about how bad I feel".

It seems like a long haul for Callum from diagnosis to where he is now and I think it has been particularly difficult because he has taken a long time to believe that he will not die. I wonder if his depression and the positive concept of suicide have added to this also, that is, the certainty of death was easier to bear than the uncertainty of living with HIV.

3.3.4. LOSS OF SELF, TANGIBLE LOSS AND DEATH

Callum has experienced loss whilst he has been living with HIV including a loss of self,

> "There's parts I can't remember, um, and so many times I've thought I wish I was the person I was pre-HIV, or pre-being told I was HIV positive".

I believe this demonstrates a loss of self because he has loss sight of who he was. He has also experienced tangible loss,

> "I had a great life, yeah, the years in [a different country] were privileged".

Callum's experience of HIV prior to his diagnosis was that having HIV/AIDS meant death,

> "...as the years have gone on and the new therapies have come out and people are not dying like they did in the 90's, that whole period from late 80's right through to the late 90's. Yeah, it [death] was just a constant topic of conversation".

This led him to withdraw from people who were living with HIV because dealing with so much death was hard for him,

"That period, the whole period from before [my partner] died...it was like a mini holocaust. The number of deaths and the number of funerals I went to was just unbelievable. Just about all the friends I had died except one who isn't positive at all and it was good because I got to the point, I thought, I didn't know anyone who was positive, I thought good because there will be no more funerals".

Callum's partner died from AIDS which was very diffuclt for him, so much so he chose not to be around people diagnosed with HIV and avoided relationship,

"So part of that might be the reason why I've not even let someone get close to me since [my partner] died, well that's not, well he died April 91, so that's 16 years, next month, that is a long time to be single, to be on my own, well I'm not really on my own I've got the dogs".

I wonder if he was avoidant of death becasue he feared dying from HIV.

Callum also experienced a lot of deaths which were not HIV related, indeed his return to Scotland was due to his mother's ill health. In a short period of time his mother, a brother and a sisiter died. The deaths of his brother and sister were unexpected,

"With my mother I knew yes I did and my sister it was so odd. She had a brain haemorrhage and was unconscious, so when I saw her she was unconscious and they said we are not putting her on life support. And I knew... I just walked in and no, I said to Sister she is going to die and she said yeap... then about 4 months later my younger brother became ill, he recovered from that, then in the November he died suddenly".

Despite coming from a large family he arranged the funerals for his family members,

"Now, how I landed the job I don't know, but I arranged all 3 funerals and did a lot, I was involved with everything with all 3, but with my brother I was left to do literally everything you have to do. Now I've never been in a position where I've had to do everything where there was no one else wanting to do anything or offering to do it...initially I thought I would be offered some help but it never came".

I wonder if Callum considers his own funeral, who will be there for him to arrange everything because no one else was forthcoming for his other family members funerals. It also appears to have been an insight for him into how his family functions and where he fits in.

There was a sense from Callum that he got the 'job' of burying his family members because he had time to do it without considering his emotions.

> "After my brother I thought that's it. I thought the rest of you are married...I'll not have to go through that again...Whereas my brother he didn't, he was separated for a long time, it really was one of us who had to do what had to be done. His death hit me a lot harder than my mother's death or my sisters, I don't know if it's a cumulative effect, but it's still very, very, it still feels very, very raw".

He appears to cope with the death by detaching emotionally from them,

> "Rarely do I think about any of these friends. Very, very rarely do I, I don't dwell on them, I rarely get upset when I think about them but I could talk about them no problem. I've not forgotten them, definitely not, I could tell you lots of things about each one...yeah that period was, I don't know I think I must have been detached from it all or something".

Callum had organized and paid for his funeral, I believe this, along with the option of suicide, allowed him to maintain a degree of control over his death.

3.3.5 COPING WITH HIV

Callum coped with death by avoiding it, therefore, he avoided anyone who was HIV+, but he then wondered if that was the right course of action because he might have missed support only another HIV+ person could have offered,

> "And it's done a complete back flip where it's continued that way and I'm wishing I did get to know someone who was HIV positive and I hadn't".

Callum initially coped with his diagnosis by taking medication even though there was no effective treatment at the time of his diagnosis. Also initially he thought he would die and indeed was told by his consultant that he would live for about 3 years,

> "For those 3 years it was in the back of my mind and I still remembered when the 3 years were up, I'm still here. So I kept thinking, am I going to see the year 2000, and I did. And then will I see the Sydney Olympics, which were in 2000, October 2000, and I did, that's what it was like for so long. And I don't think like that now".

He continued to live and over time he realised that planning and diversion helped. After about 8 years he started to plan for the future including moving back to Scotland,

> "Then, oh the next thing was I decided to make plans to come back to Scotland, so I thought that'll take me a few months to organise all of this, because I've got 3 dogs as well, there's a lot of, the sort of like, logistics and planning, a lot of work but I was determined".

Accepting his HIV had been difficult for Callum because he had not been able to find any positives from having the virus only the losses.

> "I would not like this on anyone. When I hear people say it was a blessing, well not that, but out of the flames a phoenix will rise, or whatever it is, that it's made them a better person, I just think god, I would rather be the way I was before than of had to have lived with this thing and have gone through the last 16 years. I would not wish it on anyone because it effects every, every, facet of my life. Relationships, family, well there is not a time I do think about it and I don't try to, I don't deliberately think of it, but it's there".

He believes he only fully accepted his diagnosis recently, in the last 3 to 4 years, but even with acceptance things are still difficult,

> "Being back in Scotland has been one, one, a tough, tough, tough, I'm going to use that word again, rollercoaster".

I wonder if this difficulty is affected by Callum's need to be more than a man living with HIV. During his interview he kept maintaining that he did not want the whole interview to be about HIV because he was more than just that diagnosis,

> "Not, I'm not that I want my life to be ruled by being positive but it is. It is ruled by, it is, but I don't want the topic of conversation to be solely about HIV... I don't want to make my whole life about HIV and AIDS, although 16/17 years of it have been...but it [HIV] has had such an impact, that I've forgotten what my life was like before."

There is still a side of Callum that does want to avoid aspects of his life using avoidance,

> "I was off gallivanting to [an English town], to check if I wanted to live there. I went down and checked it all out and I thought no I don't want to move. I thought I want away from paranoid problems, brothers and sisters not talking to me, I'll go away. I know I can't go back to [another country]".

He seems able to keep an open and positive mind generally about HIV and believes his time spent in a different country helped with this,

> "I think the years in [another country] made me the way I am now, open, yeah, very open and I will talk about everything and anything, it doesn't embarrass me but I think here it does, I think here people are hung up"

He also believes that HIV needs to be fought in order to survive,

> "I'm a fighter, yeah I believe I will fight, I won't give into anything, I wouldn't even stay in bed if I have the flu, I just won't lie down."

Callum had experienced anger as a result of living with HIV. His brother would not allow him to disclose his HIV status to his niece and nephew which made him angry. When his brother justified his decision about the disclosure Callum felt unsupported and stigmatized by his 'weak' brother.

"I was really angry and annoyed, so I said I've got a blood disorder and I've got to take these pills, that's how I got out of it".

3.3.6 WORK, HOUSING AND RELATIONSHIPS

Callum invested a lot into his career and appeared keen to return to the work force,

"Yeah, and a lot of my energy went into my work, all those years from 76, yeah right through to 2002 when I gave up [my career]...tomorrow I'm doing what's called a [named] course because I've not worked since 2002, I've done a fair bit of voluntary work in there though...part of me thinks I should try to get back into the work force...the next 4 days and 10-4.30 and I hope I can get through this".

He was concerned about being able to complete the training he was undertaking with a view to returning to work. I wonder if a lack of socialisation and concept of self were a driver for Callum to be so keen to return to work, although the period he had not worked was the period of time that he had noted his physical and mental health had improved the most. He would also benefit financially because even though not working was the best course of action regarding his health, adapting to a life on a low income was difficult,

"I was housed in probably one of the worst parts of Scotland...I had a car stolen, now I don't own a car, there just seemed to be one thing after another, after another".

Callum talked about being asked what he did for a living,

"When you first meet people they say what do you do, I still won't tell them I'm not doing anything, I will not, I tell lies".

This apparently simple question highlights so many issues for people living with HIV, that is, disclosure, stigma and anger or hopelessness for not being able to work, for example. In order to cope with this question Callum would just lie, this may

well highlight that he had not fully accepted his HIV status but given his open stance to life, it probably demonstrates an adaptive coping strategy.

When he was initially diagnosed with HIV Callum used support services and found them very helpful. On his return to Scotland he sought the support of his family which he never received,

> "I came back every one or two years to visit family in [Scotland]. I kept in touch with phone calls and letters, I always knew what was going on with my family although I am sure none of them had a clue what was going on with me. Still, to this day, they don't seem interested and I've found that out, but that's just the way it is...I'm on the perimeter of their lives, they've got their own lives, you know, with their families. Whereas ... my family are my 3 dogs. I also happen to have 2 sisters and 3 brothers who I don't look upon them as being my family anymore".

I would imagine he feels let down by his family and pushed out at a time when he needed support and acceptance. Due to his families reaction he approached support agencies and initially found what he was looking for, that is individual support because he had found meeting friends difficult since returning to Scotland,

> "I got involved with [a system] that [a support centre] have and I've had two terrific buddies. The last buddy I had was terrific at helping me through the two deaths I had last year, um, and he was a terrific person and ended up, we were good friends long before he left to go and live [away]...then I applied and I didn't particularly like the person, so I thought no, I don't want to do this it feels to manufactured, I don't want a manufactured friend".

After that initially potitive experience which ended up feeling false, he sought out support in a group format,

> "Two years ago, I heard about this group, I had been thinking, because in [another country] there was a group which I had helped set up just before I left, and we met every week. All ages would turn up and we discussed everything and anything. Ever since I came back to [a Scottish city] I've thought I wish I could set something like that up [here]...it was good, I really enjoyed it and the role I did, the numbers were getting bigger and bigger and it was becoming all established...we worked out our philosophy and all of those sorts of things done and out the way, organised trips on opposite Sundays, but still drew on an older crowd, a lot who were retired, I mean I was the youngest one there...eventually

> after a year I just said, it was not long after my mother had passed away, I thought to myself I've done this for a year I want to hand it over to someone else".

It would appear that the group offered a lot to Callum and vica versa for a period of time.

Callum also talked about romantic/sexual relationships

> "I've been single ever since [my partner] died and I've not met anyone since [my partner] died...I've not had any connection relationships for years. I'm completely off sex, well now I think about it, I don't want it and I don't know if I could".

He appears to have diffiuclty with connected relationships, when he seeks them out (for example, with his family and his partner) things are good for a while and then it is taken away from him. The effect of having experienced so much loss has made Callum withdraw from relationships.

> "I'm sure it wouldn't to some people, but to me it would feel like a burden with the, all the, he's got chronic fatigue, he's got sleep apnoea, he's got bouts of depression, he's got to take these pills twice a day, he's got to get injections twice a day, Doctors visits and all this stuff. I just think it would be, I don't know if I want to burden anyone with that. I'd burden myself with that but, well I've got two choices, either you do it or you don't".

It appears that he would have difficulty letting someone into his life when he has been let down by others so badly in the past. He is a caring man who appears to thrive from having responsibility and closeness but he has also experienced the loss and it would appear, weighing the two up, the loss was harder to bear.

3.3.7 SUMMARY

Callum denied his sexuality and was engaged to a woman. He moved to another country to get away from his family, it was there he expressed his sexuality for the

first time. He believes his partner was living with HIV when they met but he would not get tested. He did not like this denial because it may have reminded him of his own denial of his sexuality which he had finally over came when he left Scotland.

He started taking medication as soon as he was diagnosed with HIV. He experienced chronic side effects with some of the first medications he took and there were issues of polypharmacy but he is still alive and believes his medication has a part to play in this, along with his fighting attitude and his dogs.

Callum has had issues with his family, feeling he had let them down by being gay and HIV+ but also they have let him down because they have not supported him since he returned to live in Scotland. He gave up a country, which appeared to represented an expressive freedom for him, for his family but there was no reciprocation other than giving him the experience of arranging the funerals for his mother, one sister and one brother. He worries who will miss him when he dies, who will bury him, therefore highlighting his unmet needs not just from his family but from life in general.

Callum said he was embarrassed to say he was not working and he was about to undertake a course to help him consider returning to work. Work meant a lot to him and although he gave it up to benefit his health, it was not an easy decision.

Callum had sought out supports for his HIV, from his family and support agencies. Initially they appeared beneficial but these gains did not last and currently his main supports were his dogs.

3.4 DUNCAN

Duncan's narrative can be covered by the themes life before HIV, living with HIV, medication, healthcare professionals and mental health, death, coping and living with HIV and finances, work, support and relationships.

3.4.1 LIFE BEFORE HIV

Duncan stated that he could not really remember what life was like before his HIV diagnosis. I wonder if this was because it was too difficult to remember what it would have been like to live without HIV.

> "...actually I would probably be as fucked up if I'd had HIV as if I hadn't had HIV...also I cannot really remember what it was like before HIV now".

Duncan talked about himself when he was younger,

> "To be honest I have vague memories of the eighties but not that good a memory, well certain memories, Maggie Thatcher, print workers, these were my college days, which were very militant. It was good fun actually. I was just as drifting in life then as I feel I am now. I would do something for a few months then get bored and move on to another job, then end up in a job which I thought was good a the time and then thinking it was shite, so just not turning in on Monday (laughing)"

He never had any ambition and surprised everyone, including himself, when he stayed in education,

> "So I decided to stay on because there was a miners strike on at the time and I lived in a miner's village. My dad worked in the steel industry which had been decimated a couple of years earlier by Maggie (laughing), so he didn't have a job, so to be honest it seemed the best idea to stay on...I didn't want to go to college,

but I didn't have a job, none of my friends had a job, my dad had no money because of his redundancy and not being able to find another job, so it just seemed a good idea to go to college".

During his interview Duncan recalled the public health 'don't die of ignorance' campaign,

"I think I was still in [an English city], I had had a gratuitous night out and was getting home on the bus and I saw that first bill board on one of the roofs coming back into [the city]".

He did not take this message too seriously because he knew about HIV/AIDS but it was perceived as an American problem,

"In those days you just don't get shagged by Americans, and at that time it was mostly Americans".

3.4.2 LIFE WITH HIV

Family circumstances led Duncan to move from England to Scotland,

"My gran became ill, I didn't have a job, so I came up to [a Scottish city] and stayed. I met a guy, moved in with him and then the shit hit the fan".

His partner was living with HIV so he had an idea that he might be as well,

"I was diagnosed in 1990 but probably knew a couple of years before then but didn't think about taking a test because my partner had KS...well I think I knew anyway, I'd had a couple of things wrong"

He only took the test because of the housing law,

"In those days there wasn't same sex inheritance so the only way to inherit a council house was, because he had been given a council house on the grounds of his ill health, I just stayed there as a partner, there were no legal rights there... I needed to do the test to get through the housing laws and all the other bits".

He remembered negativity surrounding his diagnosis and the expectation of death,

"They told me I was going to die, I thought no I'm not, I think I have the bottle to keep going here. So they were quite negative at [a clinic] at that time. I guess you can understand it because...there was a death a week at that time".

His reaction to his diagnosis, especially when it was given in such a negative manner and considering his partner was dying from HIV/AIDS, was very responsible and unemotional; I wonder if he was denying his diagnosis in order to cope with the probable death of his partner.

His reaction to his diagnosis was to expect death,

"I think the thing that always knocked it back to me was the time my partner was ill and I was probably beginning to accept my own mortality, that I was not going to be around for much longer. I took all of the money out of my pension, I thought what's the point I'm not going to live anyway so I might as well have that money".

Duncan remembers the response of others to HIV,

"There were reports of people being fire bombed, bricks through windows, graffiti outside your house...I woke up once with next doors cat nailed to the front door, so I know what it can be like in some estates".

I believe a comment he made highlighted 'felt-stigma[8]',

[8] Discussed further in section 4.1.1.1 below

"I think it was more the fear of the unknown because you had heard and read things in the paper at that time, very negative reporting, so to be honest you just didn't want to become victim to that, so you just kept your gob shut".

He acknowledged that few actual incidents were apparent but they were occurring,

"I think there were only one or two at the time, it was fairly easy to keep it to yourself in those days of discrimination, I was seeing it happen to loads of close friends".

He talked about how he coped with stigma he had felt and directly experienced.

"I keep a low profile in my home environment".

But he also has chosen where to live, that is, in an area with others who have experienced deaths due to HIV/AIDS so who are more educated about it and more accepting,

"Yes, I am more open about my status. Most of my neighbours know my job and a lot of the neighbours have lost a relative up at Milestone, which is probably easier for me where I live...if it wasn't housing association without IV drug background where there is an increased prevalence of HIV and Hepatitis. Whereas if I ended up in the private estates I wouldn't end up with the same contacts, you know when there are kids around; vigilantes and so on."

He acknowledges that living elsewhere might be more difficult and lead to undesirable behaviour from his neighbours. This highlights how Duncan must feel a lot of the time, he must feel ostracised by mainstream society because he feels more at home with marginal groups.

Stigma also impacts on disclosure and Duncan has been cautious to whom he discloses. Over time he has become more open about it but it is still stressful for him,

"If you meet someone in the situation where you haven't divulged your status I think you give your self more stress thinking I'm going to have to tell them and they'll not take it too well because of the fear of the unknown or the uncertainties about it or they just don't know enough, so it is easier just to not enter into a relationship with them".

I think Duncan's experience highlights the stress and conflict people living with HIV have about disclosure, to the point of avoiding relationships.

3.4.3 MEDICATION, HEALTH CARE PROFESSIONALS AND MENTAL HEALTH

When Duncan received his diagnosis of HIV he assumed he would just die because that was his experience of the virus and this affected his attitude and outlook,

"...what is the will to go on anyway when you're going to die anyway".

Then after a period of time his attitude appeared to change,

"...and I didn't want to die in the way that everyone else was dying".

He appeared to become more defiant of death but he still accepted that he would die.

Duncan's initial experiences were dreadful due to the side effects,

"1998 I started medications, unfortunately they didn't work that well for me, lots of side effects...unfortunately I did get a really bad side effect from the DDI, it stripped out the lining of my intestines and I ended up bleeding profusely. So it took about another 6 months to repair the damage of the drugs so I wasn't at my highest. I think it was just something from the start because I have allergies to some of the medications. The first couple of times they prescribed and I ended up

really ill from something they had prescribed me and taking months or two to get over"

As a result he became very interested in all of his medical interventions and questioned all of the medical decisions,

"I would question everything they would give me, am I ok with this, there's nothing in here which will give me a bad, you know and make sure that research is done you know. I don't want 3 or 4 months being burnt from head to foot, which happened with antibiotics, one of the major ones for PCP is a sulphur based compound, I have never been so ill. I was burnt form head to foot it was 2 months before I could stop itching, scratching. So to be honest I was always questioning".

Generally he believes his experience of medication has not been too problematic which is interesting given the severity of the side effects he encountered when he was initially introduced to a combination therapy,

"I've come through relatively unscathed, which is good for me mentally. If I hadn't passed from one set of drugs to the previous ones with adverse effects I would probably mentally be lower than I am".

Possibly he felt he could not complain because he was alive considering he knew what it was like to die from HIV/AIDS becasue he had nursed his partner until he had died, which would have put his own experience into context.

As well as questioning the medical care he has been given, Duncan also acknowledged that he was not the only person to do this, indeed, it was apparently common for people living with HIV.

"They [HIV doctors] realise we have self interest. If a new drug comes out we think is that going to be better with less side effects, less dosage...we are going to go for it. Plus we know, or we see others having side effects that maybe we will get, you end up going into the doctor and saying I don't want those ones, or

saying the drugs I do want are that, that and that, are you ok with that, will you prescribe that? You then wait for the doctor to give an opinion".

This highlights a flexibility of the health care professionals to work with patients. He was not as positive about all aspects of his medical care though,

"Over the years I've been getting my medical care from [a clinic] here...which is fine, it is a teaching hospital but there is a certain point when you cannot be arsed being the guinea pig every 6 months for the new doctors doing their usual rounds. Actually why should I share my history with them when they are only here for 6 months, they don't know about my care and I've just had to explain to the last one why my medication that I am on is different to what most people are on."

He also implied a degree of mistrust in aspects of his medical advice but this might have been unprocessed grief presenting as blame because he was unable to accept what had happened as a result of medical decisions,

"At some point I realised it was safer to not be on some of the wards, the big open wards, because their hygiene and cross-contamination was not the best in those days...The district nurse thought [my partner] could do with some medical attention but as soon as he was admitted to hospital he got another infection and that's when it attacked his brain. In those points I feel a little guilty, I think I should have stood my ground and not listened to the district nurse, but I didn't have the knowledge then that I have now, so. With hindsight I probably wouldn't have done that".

He felt guilty and responsible for his partner's death, I wonder if he has been able to process this guilt now or if it still lingers which is why he is still unwilling to accept care from junior doctors and questions the care he is given so readily.

Duncan commented upon the changes when HAART was introduced,

"It was good to see people recover and begin to look well, put on weight and you know, it was quite nice not to have to go to funerals all the time".

He also considered a time pre- and post-HAART,

"I've been in bars when people have died going out for their last drink, but you don't see that now, you don't see people ill out in bars".

Both instances concerned less death and ill health.

Duncan had a difficult time adjusting to a treatment combination that worked for him but despite this managed to remain optimistic about the future,

"I have seen so much change in technology and you know how you can get treated and what have you, so who knows what the next 10 years will bring. I don't think it'll be eradicated but, in the Western world, who knows. It certainly is improving a great deal".

He did have concerns about the effects taking medication might have given that it had not been rigorously tested,

"The thing is you don't know in terms of longer terms, the drugs are only tested short term, stage 1, stage 2, stage 3 trials and then going out on the market...what's 20 years of these drugs doing to do to my body, all of the side effects, will all the organs need to be transplanted because everything fails over the years, the liver etc, etc".

Duncan also acknowledged that he was in a dilemma because he may well have had concerns over taking the medication but if they did not take it they would almost definitely die but taking it could kill him also.

"[A medicaion] which wasn't something that was giving me any effects but the results were showing effects, which was raised lipid levels and cholesterol. So it was saying I'm not going to die of HIV but I'm probably going to die of a heart attack because the cholesterol levels were going through the roof at that time".

It would appear that he considers that he has had more issues with his medication than his HIV diagnosis per se,

"I've had times when my health has not been too bad, I've had pretty low CD4 and high viral load etc. I've always ended up with more problems with my medications than I ever did from the actual HIV itself".

Duncan first talked about his mental health in relation to his partner's death,

"Mental health has had its ups and downs. It was a really traumatic time losing my partner...um, he died in 1992, basically after then it was a bit of a low, I was still working, but to be honest my health wasn't doing too well but I kept working".

After his partner died he had to think about his health and well-being which I believe he had ignored until this point. At this time he also had thoughts of suicide as a way of coping with the conecpt or death and to maintain some control,

"I did hit several lows, thoughts of suicide, and I had a stash of drugs I had kept from when [my partner] was alive, it was easier to put your self out of all of this misery, so I had that stash".

When Duncan did not die and then when he found a treatment regime that worked his mood also lifted and the suicidal thoughts went also. Recently he has been thinking about the longer term effects of the medication, implications for his mental health, and the idea of using suicide to cope returned also,

"I do sometimes get worried about my health, well mainly my memory. I read all the things about HIV and damage to the brain and dementia and I think, I used to be forgetful when I was younger...so I wonder am I any different now because no one has really taken those cognitive tests and things from those days to now, so is it just me thinking I'm going a bit ga ga...Yeah it's still there [low mood and suicidal ideation], so I wish I hadn't have got shot of them [stash of drugs]".

Duncan talked about a group he was a member of and how the conversation often turned to suicide,

"We ended up having lots and lots of conversations about what was the most painless way to kill yourself. I think we ended up deciding that alcohol and hyperthermia was the most, through our research, was the most pain free way of doing it".

As well as suicidal ideation, Duncan had also used alcohol to cope,

"I ended up at the GP a few times, never for anti-depressants, more for sleeping, I had real problems sleeping, but I found that sleeping tablets didn't work for me but a bottle of alcohol, of some description, worked even better (laughing)"

When duncan was first diagnosed with HIV it would appear that he had concerns that he would contract dementia. In order to cope with this he has always considered suicide. He also talked about his flucuating mental health and the increase in suicidal ideation when his mood was low.

3.4.4 DEATH

Duncan remembered how death was accepted and expected when he was first diagnosed,

"It was accepted then, because the next time you saw them it would be at the crematorium".

Personally this was also his experience because he had nursed his partner until his death.

"So that was a traumatic time for me in terms of watching someone die and, to be honest, wishing them to die because it wasn't that nice... I must admit the worst thing about watching someone, especially someone you care about die, is it is kind of frightening and seeing a dead body and things like that. Hearing their last breath is fairly traumatic".

His partner had developed dementia when he died and this effected Duncan in terms of the change in his partner and also his fear of also developing a dementing illness,

> "He was ga ga at that point, he was not the person I had spent the last 5 years, well 4 years at the point, with".

When he first spoke about his partner's death he was very practical and unemotional. When this style was highlighted to him he reflected upon how difficult that period was for him. This emotional avoidance might demonstrate how he coped at the time

> "...so that was a traumatic time for me in terms of watching someone die and, to be honest, wishing them to die because it wasn't that nice...I must admit the worst thing about watching someone, especially someone you care about die, is it is kind of frightening and seeing a dead body and things like that. Hearing their last breath is fairly traumatic".

The message of death was also apparently conveyed in health settings,

> "They were really negative when they gave you the diagnosis, they actually said you were going to die...I guess you can understand it because people were, they were diagnosing another death every week up there. At [an HIV ward] there was a death a week at that time".

Duncan remembered when medication was introduced so people were not dying from HIV but he noted that others were dying for other reasons,

> "...there was a time with the medication, but my family were dying, aunts and uncles here in [a Scottish city] were all dying, so I was at their funerals all the time, rather than other funerals, so it is not just HIV that kills you".

I wonder if for a young man HIV/AIDS opened his eyes to death prematurely and when people stopped dying from HIV/AIDS he was then able to see it elsewhere.

Duncan had considered suicide for himself as an alternative choice to dying from HIV (see above). He had also considered assisting his partner with his death when he was dying from HIV/AIDS and had contracted dementia,

> "I suppose in some ways in terms of my partner, I had that stash, he had that stash, but in terms of him losing his marbles sort of thing, he was not of sound mind and body etc. etc. to take his own life. So if I gave him that stash I would have been up on, you know, whatever, whatever, it could have been one way or the other".

Watching his partner die must have been so painful for him and left him feeling helpless to do anything, therefore assisting him to his death would have given him some control back in their relationship.

Duncan also commented that after the drugs were introduced even though the rate of death fell dramatically and the climate changed from one of certain death to an uncertain life, which was further complicated because some people still died,

> "Um, but it was weird because there were still people dying but you could never work out why some people didn't do so well as the others, but then we didn't know anything about drug adherence and resistance, that wasn't until later. Several people were little bit of a party animal and you knew damn well they never took the drugs as prescribed".

Ultimately Duncan never thought that he would still be alive and having to live, he thought that because he had been diagnosed with HIV he would die,

> "...things I thought I would never have to do, because back then, back at the start, every other week you were at a funeral and it just seemed to be that everyone was dropping like flies".

He also believed that death was easier for the person who died rather than those who were left behind.

"...it is easier for them because they die, but you're left alone"

3.4.5 COPING AND LIVING WITH HIV

Duncan believes he has managed to stay positive even though this was contrary to the climate around him,

> "I think I've always had quite a positive attitude. I mean, they were really negative when they give you the diagnosis. They actually said you were going to die"

Duncan uses humour to cope,

> "I've got a black sense of humour, I've always had that slightly warped sense of humour".

He also uses altruism, a sense of control over death by considering suicide, alcohol and avoidance,

> "Most of the time it was pure, not pure escapism, just going out for a drink with friends and invariably a drink would turn into going to [a club], which would turn into dancing out of your face until 3 or 4 in the morning. Then going home with whatever stranger who said yes to you, thinking you might as well. Drink can occasionally impair your better judgement. Er, I would wake up and not have any idea what part of Edinburgh I was in and how to get home, the usual. But then I think, to be honest, I began to appreciate what I had had".

It would appear that alcohol and sex helped Duncan to move to a place where he could reflect on what he had in his life rather than just focusing on living as fast as he could because he was soon going to die. I believe it also highlights his desire for normality and a relationship.

After a period of time he began to trust in a continued life,

> "I didn't think I would hit 30, never mind 40. I'm going to have to do 50 now, so those are quite. Things I thought I would never have to do, because back then, back at the start, every other week you were at a funeral. And it just seemed to be that everyone was dropping like flies, so I don't know what was different between me and everyone else where it seemed to progress quite quickly".

Living brings other consequences and he remembered a time when he thought about these,

> "I could have [stayed on benefits] but it would not have been enough to buy the flat and I thought I think my health and well-being are going to keep on improving so I have to get back into work and pension. If I don't get into work soon I'll not be able to buy this flat. I think I was beginning to realise at that point, what probably about the turn of the century that I needed to go back to work in terms of property and pension. If I don't do this I'll end up in old age in poverty".

Duncan appeared to have been a man with no major ambitions or goals in his life and he thinks this has helped him coped with his HIV diagnosis, possibly because it minimised the tangible and financial losses because these were of no concern prior to diagnosis. He did fear death but appeared to accept the certainty of it. The move from the certainty of death to an uncertain future has been problematic for him and made him realise that he has fears which need to be addressed in order to continue to live successfully with HIV.

Over time it would appear that HIV was not as important in his life,

> "It isn't the first thing I think about in the morning, it use to be what a hangover and who is this person, how am I going to get shot of them, or where the hell am I, it was never HIV first thing".

It would appear that Duncan has now accepted his diagnosis, that he will continue to live and this may or may not involve a significant other. To stay well he needs to think holistically not just medically,

> "Yes through experience I've learnt my health and well-being isn't necessarily going to have a medical solution".

Duncan fondly reflected on the time when HAART had recently been introduced and people were no longer dying but it was too early for living to be accepted,

> "I do miss those days, after my health began to improve, I was on Incapacity and got Housing Benefit, but having the time to go out and enjoy the cinema, and go for trips out and have my health and well-being and free time, being able to sit in a café. Whereas now I do 9-5 get home and am totally knackered, especially after I've done the washing and the cleaning I'm off to bed and not really having a life any more".

This appeared to be a reprisal when the concept of a future was novel yet expectant and the demands of life, for example, work and finances, were not yet applicable.

3.4.6 FINANCES, WORK, SUPORT AND RELATIONSHIPS

When Duncan was diagnosed with HIV he thought he would die so saw no need for savings and a pension. Now nearly twenty years on he is still alive and has had to deal with the consequences of decisions made in a very different environment,

> "Now I have to think maybe 10 years out of employment there, that's my pension so do I have to do old age and poverty or think of some other options now to pay my way? It is also thinking am I going to do this for the rest of my life, am I going to go back to college and pick up where I was? I have no idea now... am I going to have to work for the next 20 years!"

These are thoughts he never thought he would have, indeed, he gave up work in order to improve his health,

> "I think it must have been 1994 I gave up work. I decided between work and benefits. I was better not working, so why drive yourself into an early grave, I might as well have a few, couple of years good times, not that you can have a good time on incapacity benefit but its better than the 9 to 5 and never having the energy left. I gave up work, I think that was when I started to improve. I could

go to the cinema when I wanted, I could relax, I could get up when I wanted, (laughing) all those sorts of things.

Duncan had been able to return to work,

"...about 2000 and then I returned to work, well stated to think about returning to work, I started volunteering here. I got back into a job, well encouraged to apply for the job here when it came up, as a support worker. I think now at that point, I've been here for 4 years. I am now questioning because it is the longest I have ever been in one job".

Quiet soon after starting his new post he had to change medication and given his past horrific experience of this he was understandably concerned,

"I have to change my drugs and that was just after about a year into work that I changed and, the thing is you don't know how you're going to go with the next drugs, the next ones might cause kidney problems, you know renal toxicity, am I jumping out of the into the fire sort of thing".

It appears that he felt somewhat supported to make this move given a scheme the employment agency have which protected his benefits for a period while he returned to work,

"But they have a thing called the 52 week linking period so once you pass that you cannot go back onto your previous benefits you have to go back to the start and work your way back up. They get you every which way. I think they've increased that to two years now. Um, so I'd say that was an issue when I got up to 52 weeks of being back to work, thinking is my health going to maintain for this long and actually I was beginning to have another problem with the drugs".

He appeared to lack trust in his renewed health and needed to know he would not make himself ill again by working and that he would be looked after if that was too happen.

Duncan has sought out support throughout the time he has been living with HIV,

> "I used to go to, there is a support group...it was very much about mutual support, supporting each other. It was very much about supporting each other about your own health or others health or loss of partner, it was good for the time, it supported me a lot".

As medical progress was made which effected people living with HIV, the nature of the support evolved also,

> "We set up a project, me and a few other guys from the support group, which was supporting each other around starting to take the drugs".

He has been successful in seeking out support from friends but has had difficulty in maintaining more intimate suppport in the form of a relationship.

> "About a year or two after his death I met someone, thought it was going ok, but then that relationship falls apart. So you start to feel, in terms of relationships, this is the last chance...I've no idea when I realised that, it was just sort of, when you meet everyone else who starts off as a romantic thing and end up just friends and realise they've never had, and they're 30+, they've never been in a long-term relationship. I think I was and it was kind of nice".

He talked about issues of trying to find a relationship,

> "A relationship with someone who was positive but, gay men, Edinburgh, well Lothian, there aren't that many, not that bigger field and to be honest, 20 years into HIV now, I've been through a fair number of them already and I've never met one I've wanted to stay long term with. I've met a lot of friends out of that but in terms of love and partnership that's not, you know, I've still got some good friends. I think we'll probably end up looking after each other in terms of a brothers/sister relationship, but not partners. So it would be love on a different level".

He goes on to talk about other issues surrounding sexual relationships for people living with HIV,

"I'm thinking longer term, things seem a bit iffy because of things on prosecutions, it makes you a bit more wary about entering into things you know gay man, anonymous sex that is very easy, saunas, gay cruising areas etc, etc. But the thing is now they're saying you know, yes using a condom etc, etc, does provide, that is safe sex, so you probably wouldn't get prosecuted, but it does say that if there wasn't onward transmission that you couldn't get prosecuted if they can prove it was you. So the element there that it might be safer to enter into a relationship with someone who was positive but, gay men, [a Scottish city], well [county], there aren't that may, not that bigger field and to be honest. 20 years into HIV now, I've been through a fair number of them already and I've never met one I've wanted to stay long term with".

Duncan appeared to be a man who was able to identify what he needed and how to go about fulfilling his needs. I wonder if this is why he feels so frustrated with not being able to sustain a sexual/loving relationship.

3.4.6 SUMMARY

Duncan was living in England when HIV was first evident in Britain and he accepted that he would have to use condoms and seeing people who were ill as a result of being HIV+ increased condom use. When he moved to Scotland his partner sero-converted and he cared for him. After his partner's death he wondered if the relationship would have lasted without HIV, this might highlight a minimization of the impact that HIV has had on his life. He recognizes that when he was younger he assumed he would have a partner and now has to accept that love might not come again. He stated that he has lots of friends so there is love in his life just on a different level. He talked about his anxiety about having sex in a relationship or casual sex, also that you need to work a little harder if you want sex when you are living with HIV.

Duncan talked about his life growing up and as a man before he sero-converted. He felt he did not really fit in at school and had no real ambition or expectations, which he thinks has helped him to live with HIV because he has less to lose compared to others. Being on the fringes of acceptance meant that he lived in an area which many would not desire, again he believes this has helped him cope.

When Duncan was first diagnosed he thought he would die and was scared of developing dementia as his partner did. He initially denied his diagnosis because he was caring for his partner who later died from HIV/AIDS. He then used alcohol, avoidance, humour and suicidal ideation to cope. After a period of time and a continued life, he began to trust in life and his coping methods developed to include goal setting and altruism. A fighting attitude along with humour, was always evident.

Duncan mentioned the stigma he has felt and had experienced, how he still feels this whenever he has to disclose and how he minimizes this and copes with it. Due to his experience with his partner when he came to the end of his life, he was sceptical of some medical advice and would question it. He talked about his often horrific experiences with medication, health care and his mental health.

3.5 EUAN

Euan's narrative can be covered by the themes of finding out about HIV then being diagnosed, ill health and changing roles, death and loss of self, living with HIV and work.

3.5.1 FINGING OUT ABOUT HIV THEN BEING DIAGNOSED

Euan remembered the first time he heard about HIV/AIDS,

> "It must have been '82, '83, when we read this magazine and saw that piece about what was happening in the states...a few gay men had fallen ill from this disease in San Francisco; it didn't say what it was...I lived in the city that was the HIV [capital] of Europe and the American tourists would get given information on the way over to say be safe, leaflets and that saying if you visit [a Scottish city] it was rife with HIV".

Soon after reading this article Euan's best friend sero-converted,

> "He [best friend] met someone and we found out, he fell ill and we found out that he had this, I didn't even know what we were calling it then, if it was HIV or AIDS, or what we were calling it".

His friend did not adjust well to his diagnosis, he was angry,

> "He was one of the first ones to contract it, but he did, and I say he did get out there, he tried to do something to put a stop to it, he got actively involved. He used to come to the café and shout his head off because he couldn't get a table for all of the fucking social workers, he could shout at people who were volunteering, he would say what's the point volunteering if you just take up the tables".

I believe this demonstrates the anger that young men might have felt when they were diagnosed and feeling ill because they were supposed to be in the prime of their lives rather than rapidly approaching the end of it. As well as feeling angry, Euan remembered other feelings,

> "He felt frightened and he felt why me"

He compared this to a time before HIV,

> "Sometimes I think the arrogance of our youth was a bit much, but then that's teenagers for you, you cannot tell them anything. It was there, it was fine, no problems, we could do whatever, it was great".

Euan remembered the circumstances leading up to his own diagnosis,

> "I had just started a relationship and that was who I had got it from...after the initial feeling bad and ill and what not, nearly dying, I crawled back and seemed to be back to my old self...".

He remembered feeling stupid and ignorant with regards to becoming infected with HIV.

> "I felt so stupid. You know I had watched my best friend be really ill and die and I had managed to remain negative. Then I had one drunk, drugged, pissed night and once, a week later, I seroconverted".

I believe he also felt that he had let his friend down by not heeding his advice and not learning from what he had seen his friend go through.

3.5.2. ILL HEALTH AND CHANGING ROLES

When he first became ill Euan thought he had picked something up whilst on holiday, he rapidly lost weight and nearly died. He was then diagnosed with HIV got well again and returned to work. Despite this being before HAART was introduced medications were used with varying success which targeted specific opportunistic infections,

> "So I carried on working, they gave me certain amounts of drugs and that, but I was perfectly fine. You know little things but nothing major that would stop me working or anything like that".

Euan appears to have had a lot of difficulties living with HIV,

> "I mean 4 years ago it was like, um, we'll give you 6 months and I was like ok ...now it just seems to be one thing after another, after another".

Also considering the side effects he has experienced whilst taking medication,

> "...you get tired, I'm really, really tired. I'm tired of the pills, of the diarrhoea, or the vomiting".

All of the illnesses appear to have effected him emotionally as well as physically, indeed, he has been told he might die on three occasions,

> "My health has been pretty bad, they've not given up on me, about 3 times they've told me to be ready. I mean even now, they go on about the drugs because after this lot there isn't really anything, so if they stop working there are a couple of things they can try but they are pretty nasty and that is about it...And you go to the doctor and you're told your results say this and your results say that, and I say but my body says, you know. Not that it's had enough but it's had another kicking".

It would appear that for him living with HIV is not just a physical condition it has a mental cost also which appears to often go unheard.

Euan also worries for other people and what costs there are for those who worry for him,

> "And then I need, some sort of confirmation from the doctor that I do still need to sleep a lot after what I've been through otherwise I feel lazy. I suppose sometimes I wonder why I'm still here. I feel guilty because I've worried people so much, they've worried, I've got better, they've worried, I've got better".

Euan has experienced loss so knows how he has been affected and therefore acknowledges that his ill health is not just experienced by him but by those who care for him also. This might be because he is used to caring for others because when he was younger he cared for his mother, he then cared for his friend and then his partner. Recently he has had to allow others to care for him which potentially might have been difficult for him,

> "I've got another partner now ...it is like role reversal he is me and I'm [my previous partner], I'm constantly needing this and that and it is great, I don't feel like it's too much".

He believed he was able to cope with this change in role because he had previously cared for his partner,

> "...in a way I suppose I was the carer again, but um, this time, this person wasn't going to get ill they were only going to get better, so in the back of his mind maybe he thinks where the hell would I be without Euan".

During his recent ill health he was aware that his relationship with his partner had changed,

> "[My partner] and I have to go away and learn to be a couple again, instead of a carer and patient. Because over the past 2 years, off and on, that's what we've been and forgotten how, you know, to be partners...I resented it to start with because I am bigger than [my partner] so I resented the fact that someone else had

to carry things for me and do things for me...I think actually it's the way he handled it made it easier for me".

Euan had experienced many losses due to HIV and it would appear that he did not want his current relationship to be one of them.

Caring for others was evident when Euan talked about living with HIV and he had made the difficult transition to being cared for because of the relationship he has with his partner, but this was still concerning physical needs not mental ones.

"It's almost like, it's nearly happened [death] so many times, you think they are thinking, oh Christ, how long is it going to take for him to get well again, now that's not what their thinking, it is what I'm thinking. I've sat and thought at the end of the day I'm so tired and I've cried and cried".

He has found gaining support for his emotional needs difficult because he apparently finds it difficult to acknowledge them himself,

"Who do I talk too, well [my partner] a lot but peoples jobs in your life are to rally around and boost you. But what I am trying to say is, at some point I thought I am not wanting to take the pills anymore just to tell you, but who do you say that to? You know, you want to talk but it wasn't something that was there the next again day but it was just the lack of energy and strength and... I hate not being able to do what I could do 10 years ago. But if someone said to be, well you're 46 now, I would be like it's 2007, 46 is not old by any stretch of the imagination. So I go away and I just, I'm quite good at booting my self up the backside. I mean I'll allow my self melancholy moments but I won't allow it for too long".

I wonder if Euan will not allow himself to consider his emotions with much importance because he feels he has let his friend down by being "so stupid" to become infected with HIV in the first place, therefore he has to cope with it and not complain because his friend appeared not too. He also appears to be someone who identifies with being the coping, supportive person rather than the person who needs help and who cannot cope, even though I believe this is a need in him,

"It is more I don't think [my partner] could not take the truth, but I have to say just listen to me I don't want to hear that I'll get better, just listen to me".

3.5.3. DEATH AND LOSS OF SELF

Euan has experienced many losses due to HIV including a loss of self,

"I think the last 3 or 4 years was when it got bad. Just not feeling good even though my results say this, that and the next thing; just not feeling great. Arranging something with people and then having to cancel at the last moment because you've got the worst sickness and diarrhoea you've had all week. Constantly thinking people and thinking, oh Jesus".

The way he feels he was perceived by others also changed after his diagnosis,

"At one point I thought there was a war on, my brother told me I don't want to be your friend you're a bogey because people were getting cancer and god knows what. And the last time I was really, really ill I just felt I had exhausted every body".

He believes others thought he was in someone way tainted because so many people around him were dying. He also experienced loss of others,

"I mean I saw [best friend] die, I saw [partner] die, and others, not as close as them, but friends."

He had a friend who committed suicide who was not living with HIV,

"He just couldn't really deal with then illnesses you know, [best friend] dying you know, he just couldn't cope with it and he wasn't HIV. It was just every single thing that happened, he just got sadder and sadder until he thought the world was a horrible place. You know...one day he found a tree and a bit of wire and he hung himself".

Euan's partner died from HIV/AIDS and he cared for him up to his death,

> "He [partner] said please don't let me go to hospital...I was supposed to be getting ready to take him into hospital for a blood transfusion and at this time I was really tired. I phoned up [the hospital] and said I cannot do this any more, I can't take care of him on my own anymore, he's starting to, there's nothing of him and I can hardly lift him because he is a dead weight...So he was fast sleep and I thought, sod it, I really need to shut my eyes. I lay on top of the bed and cuddled him and when I woke up he was dead. I was just worried he heard me and gave up, but it was nothing to do with, but I was".

He remembers how he coped immediately after he had died,

> "I tried to talk but, waking up with someone dead in your arms, it's just, it's unbelievable. I just cannot describe it. When he died it was automatic, he didn't scream and cry, it was just like ok, pull yourself together, you're in your house and you have a dead body in your house. So you need a doctor, you might need, you don't need an ambulance, but you need a doctor....she was brilliant, she was round in 2 minutes, then his mother ...she left and I went into the room and I washed him and brushed his hair, and put a clean top on him and started to close the curtains and put a soft lamp in it and put his head on a soft pillow so he looked like he was asleep. I had to hold his eyes down because they kept springing open. When people came round they said he looks so peaceful. They think I woke up with that, no, I woke up with, a body all contorted, his mouth hanging open, he was just a corpse. Dead".

He appeared to cope with the death of his partner quickly and even put it into some kind of context soon after his death,

> "I switched the telly on and it was, when there were the rains in Mozambique and people went up trees. There were pictures of people up trees, a woman gave birth up a tree, and not only people crawling up the trees but snakes and lizards and anything else that creeps along the ground that needed to get away from the water. And I thought well, at least I'm not up a fucking tree. You know what I mean, I'm sitting in a nice flat, the phones been ringing non-stop, I've got friends coming round, but I'm not up a tree".

By the time Euan experienced his partner's death he had already experienced a lot of loss and I wonder if this helped him to cope when his partner died. He had also

cared for his partner and probably acknowledged the change in their relationship from lovers to carer and patient.

The amount of death Euan had experienced was evident throughout his interview and the way he talked about the death of his partner made a big impression with me after we had finished talking. I felt overwhelmed by the deaths, as he must have, but also struck by how he appeared to cope with the loss of someone he obviously cared about so much and had adapted his life to care for. I also had to bear in mind that Euan was also living with HIV at that time and had his own physical health concerns.

His capacity to cope also appeared to surprise him,

> "Luckily enough I was strong enough and you know, between the two of us I managed and I looked after him for, well I always looked after him, but I gave up work and looked after him and he died in 2000".

He is also aware of the volume of death he has experienced,

> "I don't wallow in self pity and I don't feel sorry for myself, but I have had a lot of friends who have died. I mean people I have, who know me, who have known me from 15, 16. A few years ago my friend, who was so successful, so successful, he had this lump. So I said what about that, he said no I have to go to this seminar in Australia, I said no [my friend] if you have a lump you don't walk to the doctors you run. Alright, fine, when I come back I'll get it sorted. That was in the March and he was dead in the October. That affected me, the same as [my best friend], [my partner]; it was because it wasn't HIV".

He talked about friends who had died, particularly his best friend,

> "Strange eh, bizarre eh, I mean I still have a picture of him up in my house; I still grieve for him you know. I mean we thought we were going to be two dotty old men, still getting on people's nerves, still being arrogant; but it didn't happen".

His comments also reflected another consequence of death, the loss of a future and the loss of growing old.

Euan remembered his friends preparing for death and remembering that he had also started to display these behaviours,

> "You start cleaning, you start seeing yourself doing things like cleaning out, [my partner] did it, [my best friend] did it, and I was half way through doing it before I realised what I was doing. You go through all your photographs and you throw out all your rubbish because you know people are going to go through your stuff and what you want them to find is the quality...I've done that a couple of times".

I believe this also demonstrates a welcoming of the certainty of death because when ones physical health was as variable as Euans had been, it may well be that the uncertainty of living was eclipsed by the certainty of death in desirability.

3.5.4 LIVING WITH HIS HIV

When Euan was first diagnosed with HIV he was caring for his partner who was very ill from HIV, and I wonder if he was able to deny his own status because his partner's need was greater. Denying his own needs is possibly something he is practised at because he has often taken on a caring role in his life, although more recently he was able to let his partner care for him. Another reason why he finds being cared for difficult is because he does not like people feeling sorry for him,

> "If people are still talking who you've met for a few months, few years, I never tell them these stories, because, one, it sounds so fabulous it's ridiculous, sorry, so far out there I mean, it's ridiculous, and two, I don't like people going ah, feeling sorry for me".

I wonder if he feels like this because it implies that he cannot cope when coping is something he has done for himself and others his whole life. In order to deal with this he finds himself avoiding others more often,

> "So I'm staying in more and doing more things on my own because when I am like that I want to be on my own than if I don't feel like it. So I'm reading a lot, um, starting to go for longer walks with the dog, but everything's solitary".

He believes he is still sociable when he is with people but just does not seek them out,

> "I'm not hiding from people, if I come across them I am still chatty. I think though I feel something is missing, weather it is bad or good I don't know, I've not had enough time being well to work that out yet"

He links this behaviour to his physical presenation rather than more of an emotional one, again highlighting possibly, that he ignores his emotional needs.

Euan uses humour to cope with living with HIV,

> "When [my partner] was really ill we even changed our names, I was nurse something or other. The agency had run out of nurses because of this pesky little person who had run them all away, so I was sent, this big bruiser me was sent as if to send him a lesson. And we carried on as if this was real, cracking jokes, friends thought we were mental, you know, but it made us laugh".

This comment also conveys the humour and also how he views him self as 'the big bruiser' who sorts things out and makes them better, living with HIV would have made him question this perception of himself. Considering humour, he commented upon how humour was used commonly among people living with HIV but also that some aspects of the humour would not be acceptable unless you were living with the virus,

> "HIV people can make really, really cruel jokes to each other that people who are not HIV couldn't even think of doing...if someone who wasn't HIV said that to you it would be outrageous".

I believe this demonstrates that there were groups of people living with HIV who used humour in order to form an identity as people living with HIV, and that this was different from people who were not living with HIV, different rules applied.

It would appear that it has been difficult for Euan to live with HIV because as a young man he was unable to undertake tasks he thought he should be able to do thus making him feel useless and worthless. He also felt guilty because he was not able to provide or care for himself and others, that is, he was no longer the 'big bruiser'.

Euan reflected upon the positives in his life and how they have helped him to cope with HIV, although the positivity has an edge of negativity about it when he compared himself to his peers who were not living with HIV,

> "I'm lucky I have got some good friends, a really good flat...I look out over the roof tops, so it is quite a good flat to get stuck in. I can sit on the balcony with the dog and I think this is alright, but then I think I'm only 46".

3.5.5 WORK

Work appears to have been important to Euan and after each illness he returned to work. When his partner became ill he gave up work to care for him. When his partner died he again returned to work, but on each return to work he status changed. He would therefore have felt uncertain regarding work which could have been an echo of the uncertainty he felt regarding living with HIV,

> "Every time you left you were down-graded when you went back and then I'm getting older so that became a bit of a worry. But I don't worry about that anymore, I used to hate going into situations where people would be like, what do you do? It used to be like a comedy sketch thing...I wouldn't say I was a

millionaire or anything but I would say I had this career that I didn't have. So I've got over that, now I just say I've retired and I don't go any further...I've thought about volunteering but I cannot guarantee someone that I would wake up that morning and be there for them".

It must have been a difficult process for him to move through to accept that he cannot return to work because of the uncertainty of his health.

"That bothered me because I liked working and I think that frustrated us here. What I cannot believe, that in some ways that I cannot pay my bills or rent and the government, well tax payers, do that for me. I really appreciate it".

At the time of the interview he was recoving from a serious illness, his need to feel valued and worthwhile was evident,

"I've got nothing to do. I potter about the house, I'll put a bit of paint up but what do you do. I mean I still sleep a lot. If I have a week when I feel really good, I feel like I'm a work dodger or I'm ripping off the tax payer. If I have a month when I feel good and feel like going on holiday, I feel terrible. So sometimes at the back of my mind when I am ill, I am justifying this money, that the rents being paid".

He appears to feel guilty for not working and accepting benefits which might highlight that he does not identify with a sick role.

3.5.7 SUMMARY

Euan talked at length about giving up work and how it took a lot for him to cope with the idea of never working again. He also spoke very highly of the financial support he receives although he does feel guilty for accepting it when he is feeling better. At these times he would not be able to work and, indeed, it might have been detrimental to his health. In between each illness he returned to work to a

downgraded position. He believes that after each illness he never returned to full health and felt something was lost.

Euan talked brightly and affectionately about his youth, he may well have had a difficulty in moving from this attitude to one of acceptance of HIV and all that entails at a time of no treatment. He also had difficulty conveying this to others, choosing instead not to admit how bad it was. The move from a strong, positive perception of himself to one of illness and death might have resulted in this lack of identity.

Euan talked explicitly about death and how he had self-isolated in order to protect himself, and others, from the loss that comes with death. He believes only those with HIV truly understand what it is like to live with the virus. I wonder if he was telling me that even his words were not strong enough to convey what it was like to live with the virus, even though they were very powerful[9]

Euan talked a lot about his partner and their relationship, how it was before HIV and how the virus changed their relationship from one of lovers to carer and patient. He also talked a lot about the memory of his partner and how it was still alive. I wonder if he has worried about who would remember him when he dies.

[9] Indeed, Euan's words affected me greatly and it was from Euan's interview that I chose my title.

3.6 FRANK

Frank's narrative can be covered by the themes diagnosis, stigma and disclosure; health and medication; multiple losses due to HIV; living with HIV and money, support and relationships.

3.6.1 DIAGNOSIS, STIGMA AND DISCLOSURE

Frank talked about his life before he was living with HIV,

> "[I was] one of these guys who just said tra la la la la, everything is fine, you know".

He was living with his partner in England and his partner had an illness which he was unable to shift,

> "We lived together and he became ill, he always had the cold, it was weird I never quite worked it out".

They had some medical friends who recommended that his partner get tested for HIV/AIDS

> "...it was friends, was how it happened, they said I think [my partner] has AIDS or HIV. I said oh god, and then he went to the clinic. I remember walking home and he was looking at me from the window and I just knew. And I remember thinking oh god and the chances of me having it, what with unprotected sex for 5 years were you know, so the chances of me having it were, you know".

After his diagnosis, Frank's partner would not allow him to disclose his status to anyone, he kept the secret until his partner's death 3 years later,

"[My partner] was one of these people who refused to admit he was HIV+ or whatever. It just wasn't to be discussed, nobody, it was quite freaky because I wasn't allowed. I absolutely adored him but it was not to be discussed with anybody, friends, nothing...it was just a, just a, the most, the most, horrible time in my life, I would ever be able to explain how I felt".

I believe this denial was difficult for Frank because it meant he was not able to access any support or deal with his own possible diagnosis.

After a period of time he did take a test and confirmed that he was living with HIV,

"[I took a test] which of course I knew in my heart would come back positive, and so I just thought, that's it, you know; this was in the days before combination therapy...I just blocked it out of my head, I thought well there is nothing I can do, what's done is done you know, so I just blocked it out of my head".

After the initial denial of his positive diagnosis he thought he was going to die and this had implications on the choices he made,

"So I had a really good life, I had my own business, my own house, everything. I sold it all".

Frank's partner's health was deteriorating so they decided to move to a city that had treatment options (although this was before the introduction of HAART),

"[My partner] came up, we managed to talk him into going, he was really, really ill in [England] and we, a friend, said the best thing to do was go down to London or go to [Scotland] and get treatment there, I think there was only AZT then.... and then, um, came up here, [my partner], this was in the June, and [my partner] went into hospital never came out, he died in the September".

After his partner's death, Frank was able to disclose that they were both living with HIV,

"For me personally, what I'm trying to say is, there was a time when I first found out I was HIV, my partner said no one should know, no body, my partner said no one should know, doink. So I had 3 years of my life where I had to lie to the closest people to me that [my partner] had a cold, or he couldn't come because he

had to work, or he wasn't, you know, I lived like this for 3 years and, then of course the shit hit the fan when it came out at his funeral".

When he did disclose I believe he thought he would recieve the support he really wanted but along with possible support also came stigma,

"[My partner] was like you must not tell anyone...this was 1991 so it was in the days that with AIDS you became lepers".

Frank felt he might be treated differently due to his HIV,

"Well yeah, you hear stories about people getting fed by trays getting put under the door, people not changing the bed, you couldn't tell any of your friends. My sister was pregnant and I was terrified to tell her in case she wouldn't let me touch the kid. People wouldn't share a cup with someone but I wouldn't do things like that. There wasn't the information there is now, in my perception I could kill someone by giving them a kiss".

And indeed this became his experience,

"There was a pub on the corner we used to go to a lot because I used to like a drink and I remember after [my partner] had died I visited the pub...they [regulars in the pub] didn't want to know you and they said all these horrible things about you, but like two years ago we were all friends, you came to my house we used to go out, you know...so you have to, well I personally, have had to become tough".

As well as becoming tough Frank has also considered the people he chooses to be friends more carefully,

"I really don't want to associate with narrow minded people anymore, that sounds really snotty, but I've been stigmatised and I don't want categorised, I'm just me. I'm not a freak and I'm not going to give you a rare disease or, it's weird".

He does not want to be seen just as his HIV diagnosis but as the person who also happens to be living with a virus.

Frank has not disclosed his status to all of his family for fear of their response and I believe he was surprised at his mother's response because she appeared to have taken a long time to accept it,

> "No one in my family knows, well my younger sister knows, my niece knows and my mother and my father and that's probably about it. I very much doubt any one else in my family knows that I am HIV+. Even my mother, she'll say are you going to the hospital about, well you know, about your, you know, your blood. And I'll say yes".

I believe he feels let down and disappointed at his mother for not supporting him with his HIV.

After having to keep quiet about his HIV status for so long when his partner was still alive and then experiencing the stigma when he was able to disclose has led Frank to be angry,

> "I would love to stand up in the room and say 'I'm fucking HIV, how do you like that'. It would destroy my family. My mother is not well, so if my mother goes, all this venom might come out, and if they don't like it I could say that is your problem and I don't like you anyway you cow, or whatever. So yeah, it'll be a, I'd love to do that, arrghghh I'm HIV+ what do you think about that".

He has experienced different reactions to his disclosure and rejection appears to be what he expects,

> "Well yeah, when I've told people before, it's happened a couple of times, they've literally picked up their glass and walked away".

When he disclosed to his current partner the response was therefore unexpected because he did not just walk away,

> "So for him [potential partner] to sit there and actually break down and cry, which was his reaction, it completely blew me away, it was like this was not what I expected. I felt sorry for him then, I was like I didn't want to upset you. I'm not having sex with you or whatever we are going to have to be very careful, if we

have a relationship there is every chance I'll be ill, you know, so this is what you have to expect, that is a horrible thing you have to say to someone, can you imagine saying that to someone?"

Frank considers HIV as a burden and he does not want to pass it on to others so he is cautious about who he discloses to,

"I was going for an operation and she [sister] stayed with me all night and I said to her I've got to tell you I'm HIV+, and it was a moment of weakness on my part. I should never have said, that's how I feel, I should never have given her that burden, but I just couldn't live with it anymore. So I thought she is just going to walk away now or stay and I really needed her right now".

In order to cope with difficult situations he often lies. For example, he is in hospital often due to his other chronic illness and at times he will be in a ward specific to this illness or one specific to HIV. Depending on which ward he is on, different people visit becasue he has not disclosed his HIV to everyone who knows him,

"I've got to balance it out, you know, a couple of gay friends will come and visit me and a couple of friends I've met through the hospital and getting treatments and that, they'll visit me in the [HIV] ward, so you know. So in a way I'm telling you I lead a double life. Half the people I know know and the other half don't. So I have to be very careful how I describe what is happening to me at the time"

Leading Frank's life sounds very difficult and often unsupported which has led him to feel as if he takes risks when he discloses his HIV status. When he discloses he never appears sure if it will lead to acceptance or dismissal. Over time it must have been difficult for him not to have internalised some of this stigma and rejection so he probably feels like a burden and a bit dangerous to be around.

3.6.2. HEALTH AND MEDICATION

Frank has another chronic illness as well as HIV,

"...having [this other disease] is extremely rare anyway but with the HIV, that's just a bit, oh my god. They said you are so interesting and I felt like a bit of a freak".

He talked about how difficult it was to live with his physical health problems and how having another puts HIV in perspective.

"Physically the [rare disease] is the bain of my life, that's the one that has prevented me from going to college again or getting a job in a bar again because I'm just not physically able to do that. HIV has just become something that is just there now, I've sort of dismissed it now but it is weird I don't see HIV as a problem anymore because I'm really quite an unusual case, it's because if anything is going to happen to me it'll be the [rare condition] and the HIV fighting against each other now for who is going to win".

I wonder how easy it is for him to be seen as himself rather than the 'freak' with the two chronic illnesses.

"So I am a bit of a freak. So when I am at the hospital all these bloody students come constantly to the room, so I have to go over and over and over, and I think to myself well they have been good to me, if the hospital had not intervened and given me the tablets I would be dead. So I try very hard to repay it but by the same token I think, oh god, just piss off".

Frank is rare in a diagnostic sense which could lead to increased attention from the medical field but also the attention can become unwanted especially if it means a loss of self. During our interview I wondered how I fitted in and if he wanted to tell me to piss off because at times he did become angry, but Frank reassured me that this was aimed at medical practioners in hospitals.

Physically Frank stated that his other chronic illness was more concern than his HIV and the combination of the two often led to hospitalisation because even though he had not had an HIV-related illness, his CD4 count had been low and his viral load high.

Frank talked about his medication experiences,

> "...it has been years of medication and carrying around boxes and taking pills at this time with food, or on an empty stomach at a certain time, and it is like this horrible regime...they put me on the course, the first one was pretty heavy, didn't do too well, was quite ill with that one. The second course wasn't too bad and the third one was the same combination that I am on now and I am now undetectable...As I say I'm very lucky, I'm on an easy combination of tablets, I've taken to the tablets like a duck to water...and even people who have been HIV for years, they get an illness, or a cold or a germ from somewhere and they cannot cope with it and they just die".

Given his protestations at being objectifed regarding his diagnosis and considering how difficult things were when he was first diagnosed with HIV, he still considers himself lucky and appears fairly positive in outlook. It would appear that not dying from HIV is something not take for granted because the risk of dying is still real even with effective treatments.

> "Combination therapy and all that is great and brilliant if you adapt to it, but it you don't, fuck".

I believe this highlights that the introduction of HAART did not eradicate all of the pain, suffering and loss that an HIV diagnosis had previously meant. It meant the introduction of uncertainity.

Frank had experienced side effects from his anti-retroviral medication,

> "I've just had an operation because of all the medication, combination therapy, I take. I developed gynecomastia, man boobs, and I've always been built like a whippet, to have breasts, it was horrible".

It would appear that his positive focus also extends to the future of HIV,

> "I have seen so much change in technology and you know how you can get treated and what have you, so who knows what the next 10 years will bring. I

don't think it'll be eradicated but, in the Western world, who knows, it certainly is improving a great deal".

It would appear that he believes that HIV could be cured or that better treatments will be developed in the future, I wonder if this is because despite saying he copes with HIV, he would still like to live without HIV.

Despite his physical presentation, Frank believed that living with HIV presented more mental challenges than physical ones,

"Now it is more mentally than anything. I have bad, bad, I have a bad, bad memories which every now and again kick in. That's it really. It is weird, when I am run down and I don't eat and what have you, then that, my count goes down and what have you, and then my recovery rate takes much, much, much, much longer and, as I say, psychologically it's a, it's a real, excuse my French, a head fuck".

He also conveys a sense of uncertainty and exhaustion, which would probably have exacerbated his low mood,

"I would just stay in the flat, I didn't go out and I didn't want to see anybody or do anything and I just got more and more and more and more depressed until I just, well I don't know really, I just flipped, I did I flipped. They took me into hospital for a while and I said to my self, Frank you're a nice person and all that crap and I got myself out a bit."

Although he has never actively sought out a way of killing himself he has thought that things might be better if he was dead,

"My hope is just to go to sleep, because I've had so many operations, my dream death would be to go to sleep for an operation and to never wake up".

Frank sought out therapy and believes he has benefited from this,

"And then mentally after all the stress I had, after the stress I had after [my partner] died, [friend] died, [friend] died, [friend] died, [friend] died, you know all my friends died, and all that kicks in again and then I become this, this, this nervous wreck... I knew I had to get this out, I had buried all this crap for years and years and years and it had to get out else I would burst...I've had a lot of counseling and lots of, you know, you must get out you must you know".

He was denied support when he partner was diagnosed with HIV and, indeed, when he was first diangosed and he knows that not communicating his experiences is not good for him.

3.6.3. MULTIPLE LOSSES DUE TO HIV

Frank has experienced many losses whilst he has been living with HIV. The way he is perceived and treated by others has changed, as well as the way he perceives himself,

"I just came from being this very strong, confident person to becoming this, I'm becoming quite emotional now, just becoming what you see now, this mess. Just, just, it was just horrible".

His perception of the future has altered also,

"I think I could have had a good life".

His use of the past tense implies that he no longer thinks the future will be as positive as it might have once been. Before he was living with HIV Frank stated he had everything he wanted and in a short period of time it was gone,

"I find it really difficult Alison to explain to you because my life went from having everything to just nothing in a year".

Part of these losses were his own choice but based on a certainty that he would die, that is, he got rid of his business, home and savings and enjoyed, what he thought, would be the remains of his good health. He then did not die and had few resources to facilitate his continued life, this has led to him feeling angry,

> "Well, no actually it is strange now actually, I am pretty resentful now actually, I think I've gone from having absolutely everything to having absolutely nothing and spent all my money, got rid of all things, got rid of this and that, think I'm going to die and now I'm thinking I've got to re-build all that now, I've got to make new friends, (sigh) and think about a future. I think I don't want to do that anymore, well I do, but I think what's the point"

Frank is not the only person in this dilemma or having to choose to re-build his life or just continue the one he is currently living,

> "I know of people who have been HIV for as long as I've been and we all think the same, our partners have died, we all had jobs, had careers and had this and that, then we all thought we were going to die so we all went mad, it was like this mad time. And now we all sit and look at each other and think we're like, middle aged men with nothing now".

Frank has also experienced the loss of his partner and many friends due to HIV/AIDS,

> "My best friend, he died, well he was diagnosed, people all around were being diagnosed, and then [my partner] died...then AIDS was becoming more, people were dying, my best friend died, my other friend died, my other friend died and just everyone was dying".

He also commented upon the experience of watching your closest friends die,

> "There was not combination therapy then only AZT which killed half the people anyway. So having the horrible experiences of watching people die in the horrendous way they die, they disintegrate before your very eyes, it is terrible"

This has led him to be fearful of who he loves because those closest to him die,

"Whatever I seem to do and what ever I seem to love or care for has died, so I find it very difficult to love".

He also has considered his own death,

"I am not frightened of death, it's weird, I am not frightened of death but I am frightened of dying".

In order to combat this fear he has considered euthanasia,

"If someone was to say to me Frank you're going to have HIV and this is going to happen, and this is going to happen, I think euthanasia is a great, great thing, and I don't understand why they don't allow it is this country...I would go to Switzerland and just get it done. I would sit on a balcony and look at somewhere nice and that's what I would do if everything went tits up".

He has seen many people disintegrate before his eyes to their death and has no wish to do the same, therefore euthanasia would be a way of having some control over his death, control that was denied to his friends and partner.

Frank also experienced the death of a close friend who did not die from HIV and this appeared to be very difficult for him,

"I had a childhood friend who had spina bifida and, em, she died, it was not AIDS related, she just had a heart attack and died, she was lucky to have lived for so long. That was a horrible blow for me".

I wonder if this led him to have to expand his belief of everyone with HIV dies, to everyone dies, which could feel more frightening and hopeless.

All of the death that Frank has experienced has made him question having people in his life because all the people he loves die,

"I'm too, life's, for want of a better word, I don't want to see anyone else die and I think to be there and get attached to someone and them die would be too much for me to cope with now".

Frank had experienced a lot of death so should have attended a lot of funerals but this was not the case and it appeared that the funerals he did attend did not represent the person whom they were supposed to be,

"He [partner] had [a pub]...it was a big gay bar in [a city]...so he knew loads of people, so his funeral was massive, absolutely massive. That's another thing at his funeral I had no say in what happened at his funeral. I had to hire my own car, I had to leave, at the end I wasn't allowed to thank anyone , I was told to leave, I had to leave and go home. The service itself was a farce, it was like, [my partner] was nothing like that, that was not him, you didn't even know him".

He was therefore denied an opportunity to mourn those he had lost,

"As I say most of my friends funerals were like that they were farces. All the gay friends were not invited to the funerals, they would have private family funerals they would be like get rid of us and pretend it never happened. So for us the grieving process couldn't happen".

3.6.4 LIVING WITH HIV

Frank has moved from the certainty of dying to the uncertainty of living with HIV, which is more complicated for him because of his other chronic illness. He initially used denial to cope with his probable diagnosis but then sought out a test and desired support even though he was not able to access it initially. He has also isolated himself to try to avoid all of the deaths as well as isolated himself mentally,

"I just get on with it, what can you do, I don't know. It's kind of not happening really, I just kind of switch off".

Over time he realised that he was living and his doctor has told him he could live a near normal life span,

> "My doctor says Frank you could live until you're 60. That's quite funny to say that, that's quite nice to say that. I could live the next 25 years like this, is like oh god, do I really need that, do I really want that".

He therefore sounds uncertain about his future, not if he will have one but concerning if he really wants one.

Frank has used goal setting to help put a frame on his continued life,

> "I think my first goal was to see the millennium or was it my 40th, which came first my 40th or the millennium. I was 32, 33 and I thought, if I live till I'm 40 then that will be pretty much a goal and then it was the millennium and then I was still here and things have just carried on".

Given his rare medical diagnoses he has been involved in medical trials and training of medical students, he volunteers for studies and, indeed, volunteered to be involved with this piece of research,

> "Like with yourself, there was no pressure to do this, it was just a suggestion. And I thought well, [my therapist] has been brilliant with me, I couldn't repay her enough and I think that, why not you know, it isn't going to kill me, you know, to talk to you"

Frank has a good sense of humour which was evident throughout the interview and which probably also helps him cope with his HIV. He also reported a fighting spirit and being a tough person,

> "I think I was a lot tougher than I gave myself credit"

It would appear that it takes a lot to maintain this attitude which he appears to be either unable to continue to do, or is questioning,

"...as the years have gone on the fight has gone out of me now a bit, I think do I really gotta do this, why, what's the point, you know".

Frank does appear to be stuck in a difficult dilemma regarding the continuation of his live,

"But like I say it is difficult to explain it to you all because of this, it is an emotional rollercoaster, I could sit here all day and tell you about terrible things, but I don't want to"

He believes others attitudes towards HIV have changed, people are more accepting and knowledgeable now but there is still ignorance and apathy,

"As I say, people's attitude towards it have changed so much now, they are so blasé about it, but they haven't, this is just my opinion, but they haven't lived through the horrors of watching the people you love and your friends die. They have no conception of how, what a horrible, horrible disease it is and how it can effect you in simple ways, a simple cold you know...you see these kids in Africa with AIDS and people here just ignore it, and I think hang on a minute my friends died like that, it was just terrible".

It would appear that he feels ignored and disregarded by the general population since the introduction of HAART,

"Well I don't know, you feel a bit like a, what's the word I'm looking for, empty, yeah I just feel empty; absolutely useless".

As well as empty and useless he also felt angry and this was evident throughout the interview.

Another way I believe Frank copes with his HIV is too defy it. During the interview he commented upon enjoying holidaying in America and questioning why he was now no longer able to enter the country because of his diagnosis,

"Like if you go to America for example, I would love to go back but I don't think I could be let in, and I think that is pretty damning. It's not as if I'm going to screw half of America, I want to go on holiday with my partner that's all. But because I'm HIV + I cannot go, why?"

He does however, continue to holiday,

"I go to Goa every year and I know in my heart I could come back with something that could kill me...for insurance purposes I never let on I am HIV because the insurance would be more than double the holiday. So what I do is I say to myself I'll put some money aside and if I am ever ill I'll just have to get myself out as quickly as I can. If I come off a bike or I get knocked down, if something happened because it would come out then and the insurance wouldn't pay out then".

I believe this is part of Frank's fighting spirit which keeps him living with HIV.

3.6.5 MONEY, SUPPORT AND RELATIONSHIPS

Frank was content with his life before he was living with HIV and receiving the diagnosis resulted in him making certain financial decisions which reflected his assumption that he would soon die,

"So I had a really good life, I had my own business, my own house, everything. I sold it all..., I just went absolutely mad and spent all my money like you would. I went on lots of nice holidays and spent money on my friends".

He reflected on how things have now changed for him given that he is still alive,

"You've spent all your money and you thought you were going to die and suddenly people are saying what about a job, how you going to get money and I'm like I just cannot do that any more, I'm not able to do that"

He is not alone, he has friends in a similar situation to himself,

"And now we look at each other and we are all on benefits, we are all reliant on benefits for your life. Because I mean what can you do, you cannot there's not a lot you can do really, well I don't think there is".

He had a strong work ethic but is aware now that he is unable to work, it would appear that he is uncomfortable with this especially given that he feels there is an expectation that he should be.

"...they ask, what do you do, and that just cripples me. I just become angry at them and resentful, I just say I don't do anything and it's, it's not nice, I shouldn't do it, but that's what I do. I should say I've not been well or I've been in a car accident or use excuses like that".

Given Frank's experience of disclosure he generally chooses not to tell people he is not working due to HIV and/or his other chronic illness.

Frank has had issues with disclosure, for example, being told by his partner not to disclose their HIV status, he has had little opportunity to receive support`. When he did seek some out he found it was not what he wanted, therefore he makes the comment that there is support available for people living with HIV but that might not mean it is suitable to everyone living with the virus,

"I would go along to [a support centre] and there was a wee group and if you weren't in that wee group you weren't accepted. So I would go along on my own and have a coffee and try to speak to people and I just thought, what's the point in this, so I went back to my flat and became a hermit...I tried to see men's gay groups and things and I just hated it, just hated it, I would go a couple of times and just think I hate it".

He did however feel supported from his sister,

"I would go through to [a city] with my sister a lot, she was really brilliant".

Although not all of his relationships have been easy and he has often felt unsupported by other family members.

Frank was avoiding other people and the gay community but was supported by his sister to consider another relationship,

> "My sister was like you must go out, you must go out. I was very lonely and I thought I must find someone"

He then found himself in the difficult situation of trying to start a relationship as a man living with HIV,

> "I wouldn't say it [stigma] was more held in the gay community, but yeah, there is a little bit more there. Don't forget a lot of people have lived through their friends dying and the horrific way they died, just watching them disintegrate before their eyes. So I guess a lot of people would think I don't want to go through that again, I don't want to see that. So like I say if you had to choose between someone who was or wasn't HIV+ who would you chose. I think I would choose the person who wasn't HIV+ because I simply couldn't stand to see".

He therefore appeared to believe he was not going to have a relationship because he would be too much for the other person to take on. He did meet another man and was surprised at his reaction when he disclosed to him because he was expecting rejection but instead got understanding and acceptance.

> "I've been with my partner for 11 years and it's going well just because, I told him actually and he was very good about it, because I couldn't sleep with anyone".

The possibility of sexual intimacy led him to disclose but I also wonder if he was trying to end the relationship before he became emotionally involved because he did not want to experience another loss,

> "Whatever I seem to do and what ever I seem to love or care for has died, so I find it very difficult to love".

3.6.6 SUMMARY

Frank was a happy, successful man with an apparently care free attitude to life. He became involved with a man who eventually tested positive for HIV and he was not surprised when he too tested positive. His partner would not let him disclose his status to anyone so he was unable to get any support. After his partner died he was able to disclose their HIV status. Along with this disclosure came stigma. On some occasions he was surprised at the reaction of others when he disclosed because they accepted and supported him, but more often he was rejected. Over time Frank became resistant to this but saw his status as a burden, he also became more cautious of whom he disclosed too.

Frank has another chronic illness as well as HIV and living with both illnesses is very difficult for him physically and emotionally. He often feels like a 'freak' because having the two diagnoses is so rare. He does often have low mood and suicidal thoughts. I think this reflects how difficult it has been for him to care for his partner and live with HIV initially without support, along with his other chronic illness. He does think about his death often and the desire to have perfection in death which he was denied in life.

Frank has experienced many losses due to HIV, loss of self, financial and tangible loss and loss of friends and a partner. He has isolated himself in order to protect himself from these losses. He has also adopted a positive fighting attitude in order to cope with life with HIV. Along with his attitude changing from the acceptance of certain death when he was diagnosed to acceptance of an uncertain life, he has noted that generally people's attitudes have changed towards HIV. He feels people do not take the diagnosis as seriously now and ignore it.

Due to his belief that everyone he loves dies he had difficult finding another partner but is currently in a long-term relationship. He still seems uncertain about his future, not in terms of having one, but if he actually wants one.

3.7 GARY

Gary's narrative can be covered by the themes of diagnosis and denial, media portrayal of HIV and disclosure, health and denial, financial loss, accepting and living with HIV, work, legislation and support and guilt and relationships.

3.7.1 DIAGNOSIS AND DENIAL

Gary recalled how the media portrayed the HIV virus at the beginning of the pandemic,

> "There was no such thing as safe sex then, it wasn't known about. If I think about when I was infected, people didn't even know about it, there was absolutely no knowledge about it. There were reports about gay guys dying in the States and they thought it was poppers that was killing them, amyl nitrate, er, it was before the virus was actually discovered".

He then considered his own situation,

> "I wasn't being overly promiscuous but I wasn't having what you would call safe sex, well safer sex I should say".

Gary found a lump in his mouth and his dentist prompted him to go to the doctors,

> "A lump appeared on my palette, [my dentist] said have you been feeling unwell or anything and I hadn't but he said you should go to your doctor...What worried me two years before I was asked to take part in a survey, something about your blood, my granddad had a heart condition and they wanted to find out if, if I had inherited the same genes or something...And what they'd picked up on was that there was an abnormality about my blood...Ithink I was 18 at the time but I ignored it. When I got this lump on my palette I started to put 2 and 2 together and that's what made me go for the test".

He was then tested for HIV and given a positive result. This was a shock despite his concerns given his experience in the research trial a few years prior. He was scared by the diagnosis but believes this was due to the media portrayal of the virus,

> "I was diagnosed Christmas eve 1986 which was quite a traumatic time for me really, I was very young and when I got told about my condition, and the um, the way the virus was being portrayed on TV, health campaigns and things were actually terrifying, you know".

When he received his diagnosis he was told he had only a few years to live. He coped with the news by denying it,

> "I basically went into denial about it for a long, long time, um, um, I actually got to the point that I convinced myself that I didn't have it cos I was ok, you know".

He also stopped having sex,

> "I didn't have sex for 3 years, I mean in any form, even when I was alone. I was scared, I was absolutely petrified, and I hated the idea of any sex because I felt that was what infected me. I felt it was a really dirty, sordid thing, it was a despicable thing, that was how I felt about it, well that was how I felt about myself I think you know, it was just projection".

He perceived HIV as a dirty and sordid thing and because he was living with the virus he perceived himself as dirty and sordid also.

Gary's denial of his diagnosis lasted for nearly 10 years when ill health led him to return to the doctor to confirm his HIV status,

> "I'd been off my work for some time ... and I would have to tell them what was going on, you know. So I went to the doctor just to make sure everything was, that I have a positive test, so another test was done to confirm it. And it confirmed it".

He remembers very little of the period of time between his two positive test results, but when the second result came he responded more adaptively although he believes he only fully accepted his status in the last 2 - 3 years.

3.7.2 MEDIA PORTRAYAL OF HIV AND DISCLOSURE

As a young man with limited sexual experience it must have been devastating to receive a diagnosis of HIV especially when the media portrayal was so damning and unsupportive.

Considering the media's representation of HIV at that time,

> "I think it stimulated ignorance and awareness at the same time; a paradox there... I think it did a very good job in frightening people and make them aware of what was going on, but it also isolated a lot of people because it attached an awful lot of stigma to people who were infected. It made you feel like a leper on a social level, I certainly did. I was absolutely terrified to tell anyone, I didn't tell a soul, I really couldn't".

Gary internalised the media's hard hitting campaign which added to his inability to accept his diagnosis or disclose to anyone. He was also in the process of accepting his sexuality when he was diagnosed with HIV and the diagnosis must have made the acceptance of his sexuality much harder, again given the media presentation of the virus being a 'gay' disease,

> "I think there is a certain shame attached to being HIV. It doesn't carry the same stigma it did, certainly when I was initially diagnosed, that stigma exists but not nearly as prevalent. I'd say most people don't worry about HIV any more. Particularly when my mother told her friends, anytime I've met any of them they've given me a hug, shaken my hand. They don't worry that I've used the cup in their house or anything...I think Lady Diana went a long way to changing how people perceived people with HIV. When she hugged people and shook their hands that made a lot of difference".

I believe this highlights the role of the media within this virus. Indeed a degree of my interest in HIV is because I remember the media coverage and the fear in the eighties. As new discoveries emerged the public appeared to know about them immediately. The coverage of HIV felt very public and I wonder what that must have been like for those living with the virus, did they feel like public property or public enemy number one.

Gary initially did not disclose his status because he was in denial but after many years he began to disclose. He remembered telling his parents,

> "I didn't choose the best time to do it. I told them on mother's day. I'd been out the night before...got very drunk and the next day...I phoned my mother...I started getting really upset and crying, she said what's wrong, it just came out, I didn't know how to stop it. I would never have planned to do it that way I would never dream of hurting her, my mother and father, that was, as I say, terrible".

He apparently felt that they would be disappointed by his disclosure which may have been his internalised stigma for being HIV+. His parents reacted differently; his father was accepting and optimistic whereas his mother was upset. He noted that a barrier to disclosure is the uncertainty of people's reactions and feeling you need to support them when you want the support your self.
Gary has felt that a barrier to his acceptance to living with HIV was other people's prejudice rather than health issues, for example,

> "The problem tends to be other people's prejudices, but health things you know, I can certainly get through them, I think I've been very fortunate"

Over time he has accepted his diagnosis and has been able to disclose more readily although still with caution.

3.7.3. HEALTH AND DENIAL

Gary has had bouts of ill health which he believes were as a result of his denial of the virus rather than due to the virus directly i.e. the result of somatisation due to denial rather than primarily HIV.

Once he was re-tested for HIV in the nineties he took medication,

> "As soon as I got on to the therapy in 95 or 96 my health did seem to improve quite a bit".

Unfortunately for Gary he still had to stop work in order to regain his health. He stated he had never been seriously ill as a result of his HIV but he has had problems with the side-effects of the medication,

> "I've never been hospitalised, well, the combination that I am on right now, or the one I was on previously, that regime is known to cause cardio vascular problems and there was a certain amount of lining in my arteries...I got sent down basically [for an operation] and I certainly don't suffer from the same amount of panic attacks and breathlessness that I used to".

Another side effect he has experienced is a lack of energy sometimes which results in a cycle of over activity followed by exhaustion,

> "Some days I have no energy, so on the days I have energy I really need to get as much done as possible because I don't know when it'll run out. Then I end up knackered and not quite right and just sluggish all of the time and that can go on for weeks. They think, they must think I'm quite mad because I'll just start painting and I'll just do it for 3 or 4 days and get as much done as I can because once I get tired I just cannot do it".

I wonder if his behaviour reflects his difficulty at accepting his diagnosis, he is still struggling against it which results in that particular cycle of behaviour.

Gary mentioned that his physical health was stable so the only constant reminder that he is living with HIV is taking daily medication,

> "I take my pills once a day, that's the only reminder I have to be honest with you. On a physiological level there is nothing untoward so I am very, very fortunate. The medication works, my viral load in undetectable... and my CD4 count is ok, so I just get on with it".

As stated above, although being HIV+ has resulted in Gary having physical health problems, he believes this was as a result of his mental health. Because he was not recognising that he was living with the virus, his body kept reminding him that it was present until he became so ill he decided to be re-tested. As well as a physical presentation he was also depressed and suffering from anxiety,

> "I basically buried myself in work to the point that I basically had a nervous breakdown and I was signed off for quite lengthy periods of time with depression and stress. Um, my health was stating to fail a bit as well, I was getting quite a lot of chest infections at the time which were very severe you know".

Once he acknowledged that he had sero-converted his physical and mental health improved and everything appeared to settle,

> "Well I guess it is like when you throw a stone in the pond, over time the ripples get smaller and smaller".

He reflected on the role of HIV regarding his health presentation compared to if he had not sero-converted,

> "My life has been turbulent but I don't think it has been due to my own personality as such, I am prone to depression but I've usually found it has been as a reaction to a situation I've been in, it's not something I bring on my self, I'm not naturally depressive, I'm actually pretty outgoing and social. The illness obviously has an impact on me as well".

During his interview Gary did not talk at length about his mental and physical health problems, I wonder if this was part of his denial of the diagnosis.

3.7.4. FINANCIAL LOSS

Gary did not talk at length about loss other than his financial losses,

> "I don't think I would be in the situation I am in today if I hadn't have been infected with HIV. I think I'd be, I'd have my mortgage paid off and I would still be sitting in my 2 bedroom flat in [a desirable part of East central Scotland]".

Talking about his losses including death was obviously very difficult for Gary because he minimised this aspect of his narrative, except for talking about financial losses. He denied his status for a long time and I would imagine he also minimised his contact with other people living with HIV so he might have been able to reduce the amount of loss and death he experienced, but it still would have been about him, so I think it is interesting that he did not mention it during his interview.

3.7.5 ACCCEPTING AND LIVING WITH HIV

Gary denied his diagnosis of HIV for nearly 10 years and it would appear that even now he would prefer to avoid it although he believes he has accepted it in the last few years.

> "When other people have told me about their diagnosis it has hit me quite badly...it is a very painful reminder of a time I think I've shut out of my memory. The first 3 or 4 years I couldn't tell you where I went to on holidays those years, nothing. It's like I've really blanked it out of my memory. Helping other people come to terms with it, I suppose, another way of my denying I've got it. It's like

its being acted through them rather than through me. But I do think I am very supportive with people you know because I know how hellish it is to find out".

Possibly helping others who live with HIV is a way of indirectly helping himself to live with the virus.

Recently Gary had started working from home and was aware this denied him social opportunities,

"I do a bit of work from home [but] there is no dynamic to it. I can pretty much predict that every day will be like this and that. I don't see people much during the week, they are working and pretty tired and what not, so I see people at the weekend...I think that is probably the case for most people (laughing)".

He appears to try to normalise himself to others but I believe he feels different because he wants to be going out and working as he was before HIV.

As well as being isolated, he also avoids his HIV. He considered how he talks about his HIV to his parents,

"It just doesn't come up in conversation because well, well, I tell them when I get good news but I don't tell them bad news. If my count is low, if it has dropped 10% I'll not tell them that...I tend not to bother about the bad news, you know, I love the good news and I tell them that and, you know, that always perks me up".

By not telling them the bad news he is protecting his parents and himself from the realities of living with the virus, but he is also denying himself possible support.

In the past he has also turned to alcohol and drugs,

"I probably and I mean, in the past I've turned to alcohol and... to drugs".

He has also again used avoidance in the form of leaving Scotland,

"I ended up going down to [an English city] because I thought it might be cheaper to live there and I thought it might be easier to get work. It was good initially, I had lots of friends but I didn't know who I could trust...also there were a lot of drugs down there and I got introduced into that...After a while I decided to come back to [Scotland] because ...it is a lot more peaceful here it's a nicer place to live anyway...I just missed the big open spaces and the sea, and friends".

Again it would appear that this worked in the short term but the gains were not sustainable, that is, he was still living with HIV.

It has taken Gary a long time to accept that he is living with HIV, he is aware of this and believes that the thought of infecting his partner may be significant in delaying his ability to accept his diagnosis,

"I think the process of acceptance was so slow because you know, feeling like I'd infected my partner that was just an awful feeling, it really was, it is terrible to think you are responsible for making someone else ill, that is, er, it is a hard one. Nothing compared to how they are feeling but you are feeling like them anyway because you are infected too".

The idea of infecting his partner appeared to have been difficult for Gary to accept but it also could have been something else which prevented him from moving to acceptance of his own diagnosis, because how could he accept infecting another if he cannot accept that he is infected. He has accepted his status,

"HIV is part of me because I've been living with it for so long and I am always shocked when I tell people that I have it, you know, because I do forget about it you know"

He still appears to have some resistance to living with HIV because he is shocked when he remembers his status.

Gary feels guilty for possibly infecting his partner with HIV and was aware that feeling guilty had an adverse effect on his health and his opinion of self,

> "It is a terrible thing to carry around, a terrible thing to carry about. That really does push your self-esteem down and down. You don't feel worthy of other people and I think that's why you end up feeling pretty apologetic about things and over compensating for things. That's what I've felt but maybe that is just me, I don't know, I don't know".

His guilt and low self esteem also affected his sense of worth,

> "I had the short term approach right through my twenties and thirties and now I realise I'm maybe actually worth something"

Being diagnosed with HIV had a huge effect on Gary emotionally and physically which then led to certain behaviours and other feelings and thoughts. Now he has been able to reflect on these negative cycles and re-evaluate his position,

> "I thought what might be particularly important might be how we perceive our selves, like I say I've over compensated for having HIV, it was like I was apologising for having it you know, and I think a lot of people get into that mind set just from little things I've picked up from people in the same situation".

People living with HIV can internalise the stigma attached to the virus and unconsciously perpetuate the negativity, for example, by self-isolating. By being aware of what living with the virus means to the individuals living with it, they can become aware of the role they play in the perception of the virus. It would appear that he is aware that he has perpetuated the stigma and has addressed this,

Gary believes that it is easier to live with HIV now, compared to when he was diagnosed, because people are generally more informed about HIV and there are effective treatments,

> "I think probably if I were to find out now, rather than 20 odd years ago, I would feel more relaxed about it. I think there is a lot more knowledge now and there are treatment options now which just didn't exist back them. Public reaction to it generally it, I don't think people worry about it so much now which concerns me to a certain extent because they think it just isn't there any more...but people with HIV are treated more compassionately and more favourably but I think we are treated fairly".

He does highlight that a decrease in people's fear does also probably result in people being more at risk of sero-converting but for someone living with HIV this makes it easier.

Towards the end of his interview Gary expressed interest in the other interviews I had conducted and he hoped he was not different from them,

> "As I say I hope I'm not unique, I hope I am like other people and there is something that I've spoken about that makes some sort of sense with regards to other people who are participating in this and it can be identified as a problem. If there are a few I don't know".

I believe this demonstrates his need to be worthwhile and I wonder if this also highlights one of the problems he encountered when he was diagnosed with HIV that made it difficult for him to accept his diagnosis, that is, being different.

3.7.6 WORK, LEGISLATION AND SUPPORT

When Gary was diagnosed with HIV he denied the diagnosis and avoided it in a number of ways including through work,

> "When I was working I was in well paid jobs you know, I was a team leader in [a company], I had a lot of responsibilities and I certainly don't do things by halves you know, I give 110% to anything that I decide to do otherwise I don't think it is worth doing".

Over time he was having more and more illnesses until he became too ill to work and he took early retirement. When his health improved he took another post but repeated the behaviour he had implemented previously so immersing himself in his work to avoid his diagnosis,

> "I found myself immersing myself and taking on too much and I ended up having to leave there with stress. It was really beginning to affect my health, my CD4 count plummeted to about 25 at one point and my viral load sky rocketed".

His work ethic was so strong, I wonder if this was indeed a huge need to avoid his HIV diagnosis, that he decided to again return to work once his CD4 count and viral load stabilised. Unfortunately this post did not work out which left him in a difficult financial position resulting in him having to sell his house,

> "I left the [job] so again I was pretty well buggered financially so I had to sell my flat which I'd got and done a lot of work on, that really, really pissed me off".

Gary then had a difficult time living with friends and family until he was offered accommodation through the council. His first property was broken into before he had moved in and then he was housed where he currently resides,

> "The first day I was in there, well it wasn't the first day, I'd been moving stuff in over 2 weeks, I'd left my laptop in one night and a new telly, a concrete slab was put through the window that night and they made off with everything".

He is certain that if he was not living with HIV he would not have lost his jobs and, therefore, would not have lost his home.

Gary stated that living with HIV is easier now because legislation has caught up, that is, it is not illegal to discriminate against an individual simply on the grounds of them having HIV,

> "There have been amendments to the Disability Act and things which mean that it is illegal for people to discriminate against you in employment matters and what

have you. Um, I just wish that legislation would have been around before I might have been in a different situation now".

Given the way he immersed himself in his work in order to avoid his diagnosis which resulted in ill health and therefore retirement or inability to work for most of his posts, I wonder if this Act would have effected him at all. Indeed, he did disclose his HIV status to the Human Resources departments all of his employers but not to anyone actually in the workplace unless it was relevant, therefore they should not have know that there was grounds for discrimination.

Gary has had a lot of support from family and friends which has made living with HIV a lot easier for him,

"I've had support from my oldest friend who I've known for about 20 years. He let me move in with him he was great once I got the job and everything. The support I've really got, when things have got bad, has been from my friends and they have been very, very good, not telling me so much what I want to hear but what I need to hear and that's always, that's the sign of a true friend. They aren't doing it out of spite but because they care and love me".

He puts himself out for others,

"If they have a delivery coming or a service engineer coming, they'll give me their keys and I'll go and sit in and wait for them rather than them taking the day off work, I don't mind, it is fine with me".

He does appear to find it difficult to accept help from others though and appears to be more comfortable helping others. This must make living with HIV difficult because at times he will need support from others,

"One of my friends who was infected, who became infected, I think it was 4 years ago, and he had just gone down hill so rapidly. I had to cook for him every night and I had to cook him a decent meal so he was getting decent food and things. But I kind of took it on myself, it is as if I was nursing myself a bit, do you know what I mean. Kind of what I didn't get. Not because it wasn't there but because I

didn't ask for it. I am a bit like that, I am reluctant to ask anyone for anything. I have trust issues on a massive, massive scale but I think that is just down to what has happened in the past, it has made me very wary of people".

He appears to have secondary gain from helping others out, he is able to provide to others what he would have liked to have been able to accept, and he benefits from this.

3.7.7 GUILT AND RELATIONSHIPS

Gary has carried a lot of guilt in the past regarding the possibility of infecting his partner with HIV. They stayed in contact after they split and even went on a holiday,

"We were on holiday a few years back, about 2001, he got drunk one night and he decided to knock my front teeth out which was pretty, no, really upsetting. It totally ruined my holiday and I had 6 months of hell waiting for a huge bridge to go across the front of my mouth".

He may have welcomed this attack as recompense for potentially infecting his ex-partner. Carrying around this guilt and the real concept of being able to infect others, I would imagine that meeting others and starting a relationship is very difficult for Gary,

"The fact that I am single doesn't help much either because you know, that is the one thing I really do not like about my life at the minute, the fact that I don't have someone in it who is important to me".

It is interesting that he sees being single as a reflection of himself although he did go on to reflect on how difficult it is to meet someone given his current circumstances,

"Well I guess if you're gay it is harder to find someone because there are less people to choose from and an even smaller percentage of people in that subset who are positive, so yes it is very difficult".

In his last relationship Gary was over compensating and giving more than he was receiving, the relationship did not last and it affected him a great deal,

"I did met a guy last year who really pressed all the right buttons and made me very, very happy and I still miss him very, very much...that caused me an awful lot of anguish over the last three months...it breaks my heart to be honest with you".

Even though he would like a relationship he appears to be remaining positive about his situation, but then he would,

"I'm sort of footless and fancy free. I'm not promiscuous to be honest, sex for the sake of it doesn't interest me. I've got good people in my life and that's what matters most, maybe that's more important. It is good to be surrounded by people who you trust and who know you, it goes both ways".

Gary has reflected on his situation and believes that he would like a relationship with a man who was also living with HIV,

"I feel to a certain extent if I am not with a positive partner, from my partner who was negative, I've had other partners since the other one, I over compensate for having HIV. You know I do a wee bit more because I think why would someone be with you because you have HIV, that sort of thought".

He believes he would compensate less if the other man was also living with HIV and this should also address his anxiety about infection.

3.7.8 SUMMARY

Gary was a young man when he was initially diagnosed with HIV. Two years prior to diagnosis he was involved in a research trial which led to him thinking that something might have been wrong. At the point of diagnosis he was unable to cope with the results so he denied it for nearly ten years. He was re-tested in 1995 and even though at this time there was no effective treatment, specialists in the profession were expecting a breakthrough at any time so his prognosis was better. Because of this denial Gary avoided and minimised his contact with other HIV people so his interview did not cover the death of friends, lovers or others living with the virus.

Gary had to stop working due to his physical health which affected him financially but also socially because he saw work as a good place to meet people. He has immersed himself in work to avoid his diagnosis resulting in health problems. He is still working part-time and from home.

Gary believes he infected an ex-partner and feels very guilty for this. He is also aware that in relationships he over-compensates for his status which is just one of the ways he is aware that his life is different due to HIV.

During his interview it was apparent that Gary often felt that he was not heard, others were making decisions for him based on his physical health. I wondered if this reflects how he felt lost to his diagnosis, that he had lost himself.

Gary talked about public perception of HIV that there appears to be more understanding which has a positive knock on effect for those diagnosed more recently and he believed that things would have been easier if he had been diagnosed later, although he now feels he has accepted his diagnosis, that it is part of him.

4 DISCUSSION

4.1 SUMMARY OF FINDINGS

Each of the men's narratives were examined in isolation and it is interesting that the themes that each man expressed were highly comparable. Indeed they appeared to revolve around 5 central themes of diagnosis, health, loss, living with HIV and psychosocial need. This section examines the similarities and differences between the seven men's narratives and the five emergent themes will be considered below including literature where relevant.

4.1.1 DIAGNOSIS

Individual's reaction to a diagnosis of HIV has been discussed by Brashers et al (1999). They found that denial and anger along with an acceptance of premature death were common among people when they first received their HIV diagnosis. Reeves et al (1999) highlighted that the coping strategies initially utilized by people were different to those used later on. Immediately after diagnosis they noted denial and anger as well as behavioural strategies, including excessive alcohol use. Over time they found humour, altruism, faith, support and balance (weighing up and dealing with life demands) were common coping methods.

All of the men talked about what their lives were like before they were diagnosed with HIV, circumstances leading up to diagnosis and their reaction to the diagnosis. Brian, Duncan, Euan and Gary mentioned how they first heard about the virus and how it was being portrayed in the media before they were living with it, or indeed, anyone they knew was. Gary and Brian were critical of the media portrayal.

Brian and Euan believed alcohol was involved in their becoming infected with the virus. Considerable evidence exists that alcohol use contributes to the spread of sexually transmitted infection including HIV (Kalichman, Simbayi, Vermaak, Cain, Jooste, Peltzer & Habilis, 2007).

4.1.1.1 Stigma

In their metasynthesis of qualitative research on living with HIV, Barosso & Powell-Cope (2000) highlighted that one of the main themes was dealing with stigma. Herek (1999) noted that AIDS stigma was universal, and it is noted in almost every piece of psychosocial research relating to HIV/AIDS (Siegal & Kraus, 1991; DeCock & Johnson, 1998; Fleishman et al, 2000; Flowers & Church, 2006; Carrico et al, 2007). All of the men except for Euan had felt the stigma that was attached to HIV now as well as earlier in the pandemic. Euan eluded to stigma but did not talk about it overtly.

Recent findings from the UK Gay Men's Sex Survey stated that 8.3% of respondents had been physically attacked and 31.7% were verbally abused because of their sexuality (Hickson et al 2007). In a study of gay men living with HIV in London, King (1989) found that 29% had received at least one negative reaction.
Green (1995) talked about 'felt-stigma', so the men might not witness or be subjected to aversive behaviour as a result of stigma directly but they know it happens and are affected by it in a secondary manner. Callum, Duncan and Frank had experienced abuse directly but all were aware of the potential, therefore, of experiencing felt-stigma.
Many of the issues associated with a diagnosis of HIV appeared to be linked with stigma. If HIV did not carry the stigma it does, maybe transition to acceptance of the diagnosis would be easier.

I did not fully appreciate the fully pervasive nature of stigma from the men's narratives, that is, I believe the men were experiencing the effects of living with a stigmatised illness but they were not overtly showing that to me. Considering the history of HIV and the link to gay men in the eighties, for example, it was assumed if you were gay you would be HIV+, I wonder if a certain level of stigma was implied which I was not aware of considering my gender, sexual orientation and age. Also the men had been living with HIV for so long, and had been living with their sexual orientation for longer, they had devised mechanisms by which they contained and coped with it.

Most of the men believed that stigma was not as prevalent today as it was when they were first diagnosed, indeed being diagnosed with HIV today does not carry the same stigma as it did when they were diagnosed. The recent increase in HIV diagnoses amongst gay men (Dougan, Elford, Chadborn, Brown, Roy, Murphy, O Noel & Dukers, 2006) might indicate that stigma is reducing. Along with effective treatments people may not be as concerned about becoming HIV+. People therefore are not as careful with safer sex practices, for example. (Discussed further below in section 4.4.1 clinical implications).

4.1.1.2 Disclosure

One of the major issues when receiving an HIV diagnosis is dealing with a stigmatised illness and how to go about telling people about it (Siegal & Kraus, 1991) or risk the negative consequences of them finding out (DeCock & Johnson, 1998).

All of the men, except for Euan, talked about their experience of disclosing their HIV status and the anger, anxiety and tension they felt as a result of disclosure. Adam, Brian and Callum disclosed their sexuality and HIV status together.

4.1.2. HEALTH

HIV is a virus which has a physical effect therefore all of the men had been in contact with physical health services for initial testing, subsequent monitoring of their HIV and regarding medication. Living with HIV also has a psychological effect and all of the men talked about their mental health.

4.1.2.1. Physical health

All of the men talked about their physical health whilst living with HIV, Brian, Callum and Frank have other co-morbid conditions which they also discussed. Adam, Duncan, Euan and Frank talked about the providers of their health care which were generally positive and collaborative.

Adam, Callum, Duncan, Euan and Frank talked about their experience of caring for others or being cared for, all of these men, except for Adam, cared for their partners who all died from HIV/AIDS. Euan talked specifically about his change of roles with his current partner.

4.1.2.2 Medication

The introduction of Anti-HIV therapy marked a new era for HIV/AIDS and led to its change in classification from terminal to chronic illness. These drugs interfere with the way the virus tries to reproduce itself inside a human cell. Although anti-HIV drugs cannot kill the virus completely, they aim to suppress the level of HIV in the blood (viral load) by reducing the ability of HIV-infected cells to produce new HIV particles which could go on to infect even more cells. HIV can become

resistant to the drugs used to treat it, and because of this it is very import to take anti-HIV treatment exactly as instructed (that is, adherence) (NAM, 2007).

Taking medication is not an easy 'cure' for HIV, indeed there still is no cure, and the medication regimes can be problematic. Siegal & Lekas (2002) in their work on chronic illness, stated that living with a chronic illness often involves adherence to a care routine for the rest of the individual's life, including medication regimes and drug side effects.

4.1.2.2.1.The introduction of HAART

It is recommended that everybody who is ill because of HIV should take anti-HIV therapy. If your CD4 cell count falls to around 200 you are also recommended to start HIV treatment. If it is between 350 – 200 and you have no symptoms of HIV infection, then the decision on whether to start treatment is guided by the speed at which your CD4 cell count is falling and your viral load is increasing. Anti-HIV drugs are most effective when taken in a potent combination of three or more at the same time. This is often called combination therapy or HAART (Highly Active Antiretroviral Therapy) (NAM, 2007). People taking HAART generally take 3 pills once or twice a day, they visit their HIV clinic every 3 or 6 months for monitoring and are encouraged to lead a healthy lifestyle. Taking HIV treatment is a lifetime commitment.

All of the men talked about medication and all of them, except for Euan, talked specifically about when HAART was introduced. Adam, Brian, Callum, Duncan and Frank talked about the search for the right combination of medication and all of the men, except Gary, talked about unwanted side-effects of the medication. The experiences of all of the men demonstrated that in order to live with HIV you need to take HAART but this comes at a high cost, that is, side effects of the medication which can be extremely difficult to tolerate, the search for the right combination and the high level of adherence needed to avoid developing drug resistance.

Adam expressed anger at the drug companies for making money out of people living with HIV and Brain commented upon immunity and resistance to medication. Duncan talked about the uncertainty of his good health and wondered if it would last. He also believed that people living with HIV have self-interest in their medical care which is not seen in many other illnesses. Brain and Duncan expressed concern about the long-term effects of taking HAART considering it is relatively new, untested, medication. Brashers et al (1999) stated that acceptance of the medication was an area to be renegotiated in order to successfully live with HIV.

4.1.2.3 Mental health

Kalichman & Sikkema (1994) investigated the psychological sequelae of HIV infection and AIDS. They demonstrated high rates of depression in samples of people living with HIV but recognised that high numbers of people had depression before their HIV diagnosis, and there was a high overlap between the diagnostic criteria for depression and HIV infection. They also noted an increased prevalence of suicidal ideation and attempts, especially early after diagnosis.

O'Dowd, Biderman & McKegney (1993) found that 90% of people living with HIV attempted suicide and that their first attempt had been unrelated to their HIV status. Siegal & Lekas (2002) stated that higher levels of depression and suicide were also noted before HAART, particularly just after diagnosis. Rabkin, Ferrando, Lin, Sewell & McElhiney (2000) investigated the psychological effects of HAART and followed a sample of gay and bisexual men who were living with HIV pre and post-HAART. They used measures of psychological distress and concluded that a clinically modest (but statistically significant) decline over time was seen. Siegal & Lekas cited another study which reported a non-significant change in depression ratings from 52-46% pre- to post-HAART.

Catalan et al (1992) suggested that as "AIDS becomes a more manageable disease there will be diminished need for acute mental health services and a greater need for

interventions supporting individuals in adjusting long-term to chronic illness related psychosocial stressors". This would still involve higher levels of anxiety, depression and suicidal ideation compared to the general population which could indicate an unmet need (discussed further in Clinical Implications below).

The men agreed that living with HIV presented more mental challenges than physical ones and depression was an issue for all of the men and was particularly problematic for Callum . Most of the men (except Euan and Gary) also talked about suicide, either their personal ideation or experience of others successfully committing suicide as a result of HIV. All of the men talked about keeping mentally well, which demonstrates an understanding and acceptance of their mental health and knowledge of what to do about it, although not all of the treatment options were adaptive. I was surprised at the high prevalence of suicidal ideation, some of which was linked to low mood and/or a way of maintaining choice over their death.

It has been suggested that psychological distress associated with an HIV diagnosis lasts for a period of time. The length of this period has been cited to last in the literature has varied from 2-10 weeks (Siegal & Lekas, 2002) up to 5 years (Courtney, Merriam & Reeves 1998). The men I spoke with did not fit either of these time periods, for most the psychological distress was still evident at least 12 years after being diagnosed. Even considering that some of the men probably had pre-morbid psychological issues, the periods of time cited in the literature appears too short. It might be that being diagnosed with HIV post-HAART leads to a shortened period of psychological distress compared to those who have lived longer with the virus. Acceptance of the diagnosis might occur on two levels, that is, a philosophical acceptance occurs relatively quickly but the full emotional implications take much longer.

4.1.3. LOSS

Finding meaning in HIV/AIDS including making sense of death and dying, as well as other losses, is needed in order to successfully adapt to living with HIV (Barroso & Powell-Cope, 1999).

All of the men (except for Brian) noted a loss or a change of self to some degree. Barroso & Powell-Cope (1999) also stated that the self needs to be focused on in order to live successfully with HIV.

Callum, Duncan, Frank and Gary talked about their loss of material possessions and status as a result of their HIV diagnosis. It is interesting that Gary was able to talk about these losses when he was unable to talk about loss of life.

4.1.3.1 Death

Being diagnosed with HIV when all of the men involved with this study were (pre-1996) meant there was an expectation of death. All of the men, except Gary, talked about death and they believed that being diagnosed with HIV meant dying.

Four of the men had experienced the death of a partner and their partner's were probably the person who had infected them, so they were experiencing their deaths whilst living with the same virus. I wondered if this would have led to resentment and anger towards their partners but this was not apparent.

Callum, Duncan, Euan and Frank found that deaths of friends and family members who were not living with HIV affected them greatly. This was possibly because they lived in a sub-culture where death was accepted but they found it difficult to

tolerate the thought that death was everywhere not just in the community of people living with, or affected by, HIV.

Frank had considered an assisted death, Brain and Callum had arranged and paid for their funerals and Euan had noticed that when he has been told that he might die he started to prepare for this eventuality. I believe there was a need for some of the men to feel in control of their deaths when they had to relinquish a degree of control over their lives due to their HIV diagnosis.

During the interviews the amount of loss was at times overwhelming to listen to especially when the men talked about the loss of their partners.

Interestingly the literature after this time (post-HAART) does not mention death or loss but referred to adjustment and adaptation to a life with HIV. People who have lived long-term with HIV have experienced loss and, at some point, accepted the loss as part of their future. Revival signified the loss of the certainty of death. It would appear that the men do not want to lose this part of their history, and indeed, it highlighted a difference between people diagnosed with HIV pre- and post-HAART.

It would appear that death was part of the men's identity and they do not want to lose the part of them that was associated with death, that is, their history and experience. This is consistent with literature on Jewish survivors of the holocaust (Garwood, 1986, discussed further below in section 4.2 coping).

4.1.3.2 Funerals

The men had experienced a lot of death so had attended a lot of funerals. Adam, Callum, Duncan and Frank had difficult experiences, which perhaps mirrored the difficulty the men had in life. Adam, Duncan and Frank all talked about defiant

acts (for example, Adam wearing a red jumper to funerals) in relation to HIV which demonstrated their defiance towards the virus.

Adam, Callum, Duncan and Frank all believed that death was easier for the person who died rather than those who were left behind which may have been due to the volume of funerals they were attending and the amount of death they were experiencing.

Euan talked at length about the death of his best friend and partner, in particular, and his comments also reflected another consequence of death, the loss of a future and the loss of growing old.

4.1.4. LIVING

A lot of research has been undertaken concerning how people cope with an HIV diagnosis. Most propose stages of coping or models (Siegal & Kraus, 1991; McCain & Gramling, 1992; Leserman, Perkins & Evans, 1992; Lutgendorf, Antoni, Schneiderman. & Fletcher, 1994; Pakenham, Dadds & Terry, 1994; Barroso, 1997; Chidwick & Borrill, 1998; Brashers et al, 1999, Reeves et al, 1999;Barroso & Powell-Cope, 2000; Fleishman et al, 2000).

Denial was employed by all of the men particularly after diagnosis but was used for differing periods of time for each of the men. Courtney et al (1998) discovered that individuals could stay in this period for 6 months to 5 years. Gary reported being in denial for 9 years and Duncan and Callum reported similar lengths of time before they started to accept their HIV. Reeves et al (1999) report a transition period that people go through in order to move from denial to acceptance. A similar period appeared to be evident for the men I spoke with because they were unsure of when they moved from denial to acceptance or how it came about.

There is literature to support that gay men are often socially isolated (Green, 1993), are marginally more likely to live alone[10] (Hart, Fitzpatrick, McLean, Dawson & Boulton, 1990, Miller, 2003; Vital Statistics, 2007) and may not have strong family links (Wolcott, Namir, Fawzy, Gottlieb & Mitsuyasu, 1986). Forming connected relationships helps reduce alienation and separation from others which could be part of the process of successfully living with HIV (Barroso & Powell-Cope, 2000). Isolation might be an issue per se but it might also come from social exclusion considering the stigma of HIV.

All of the men, except for Duncan, talked about isolation to some degree due to living with HIV. This might have been out of necessity because of the unwanted side effects of medication.

When the men were diagnosed with HIV there was no effective treatment although some treatments were being used to combat specific opportunistic infections, so all the men needed to come to terms with having a terminal illness. All of the men expressed uncertainty about their futures although they all now accepted their continued lives with HIV. All of the men experienced the introduction of effective treatment for HIV so have had to change their outlook from certain death to probable life. Many authors have talked about uncertainty in HIV/AIDS (Weitz, 1989; Green, 1993; Brashers et al, 1999; Barroso & Powell-Cope, 2000; Siegal & Lekas, 2002). Siegal & Lekas (2002) stated that uncertainty had always been present in HIV/AIDS, since the introduction of HAART it had just changed from when will I die, will there be treatments available to when to start treatment, will treatment work for me, what will side effects be, for example. With people living with HIV due to HAART, this experience of revival or reprieve will also lead to uncertainty (Siegal & Lekas, 2002; Brashers et al, 1999).

[10] In 2001, 32.9% of the Scottish population lived alone (Miller, 2003) compared to 36.2% of the Scottish male population in 2007 (Vital Statistics, 2007)

For some men there seemed to have been steps they had gone through in order to trust in a future which would fit with some of the theories that people go through stages from denial to acceptance of HIV (Siegal & Kraus, 1991; Brashers et al, 1999; Reeves et al, 1999; Barroso & Powell-Cope, 2000).

Humour (all of the men except Callum), altruism (all of the men except Euan and Gary) and goal setting (Adam, Brian, Callum, and Frank) were cited by some of the men as ways to cope with HIV.

Reeves et al (1999) cited altruism as an adaptive strategy to living with HIV. Vailliant (1977) in his model of adaptation believed employing the defense of altruism was more adaptive than the use of neurotic or psychotic defenses.

Reeves et al (1999) stated that Freud apparently considered humour as the highest of the defense processes. In their work looking at adaptation to HIV, they stated that humour was used, along with other strategies, in a transition period to help individuals move from denial to acceptance of HIV.

Maladaptive mechanisms were also mentioned by all of the men (expect Euan), including drugs, alcohol, contemplating suicide and running away. Reeves et al (1999) noted that along with affective coping mechanisms (for example, denial), behavioural ones were also common (for example, excessive drug and alcohol use).

4.1.4.1. Attitude and Emotions

All of the men agreed that in order live with HIV you have to have a fighting attitude and not give in. Leserman et al (1992) in a study of 52 asymptomatic gay men living with HIV, noted the use of 4 coping strategies, one of which was adopting a fighting spirit.

Most of the men (all except Euan and Gary) also stated that they had decided to live, therefore implying that if one does not have a fighting attitude and decide to live with HIV they would die.

As the men spoke of their experiences of living with HIV a range of emotions were present including anger, guilt, frustration and sadness. There was a limited presence of positive emotions.

All of the men had experienced anger, they appeared to be angry at the losses they experienced due to living with HIV, their lost status, money, contentment and acceptance, and in return felt stigmatised, excluded and had to cope with mental and physical illness. The men also said they felt worthless and useless (all except Brian and Callum) which would have been a difficult place for men to be when they were used to being providers, strong and vital men. Adam, Brian, Callum, Duncan and Gary also stated they had felt fearful or worried at times whilst living with HIV, mainly due to the uncertainty the diagnosis brought into their lives. Gary wondered if he was different from other gay men living with the virus.

Guilt arose in a number of places for some of the men (Adam, Duncan, Euan and Gary). Gary felt guilty for, he believes, infecting his partner with HIV. This guilt made his acceptance of his diagnosis more difficult. Some of the men expressed survivor guilt.

Duncan fondly remembered when he had adjusted to a HAART combination so felt well but there was no pressure to return to work, also because of medication other people were also not ill or dying. Frank simply said he felt empty.

4.1.4.2 Living with HIV

Ultimately all of the men involved in this study were living with HIV. Since the introduction of HAART there has been a 'revival' (Brashers et al, 1999) or

'Lazarus[11] Syndrome', that is, significant improvements in health and functioning as a result of current medication advances (King, 1997; Thompson, 2003). Living with HIV is not simply about still being alive though and Siegal and Lekas (2002) highlighted that in an era of drug-resistant viral strains, the risks of re-infection and co-infection may play a considerable role in shaping people's relationships.

All of the men talked about how they live their lives and how this has been shaped by their HIV diagnosis and how their lives had been shaped was different for each man.

Adam, Brian, Duncan, Frank and Gary all expressed specific hopes and fears for the future, a common one being a cure for HIV. Adam had concerns over the HIV situation in other countries where there were limited treatment options, Brian worried about the future status of HIV and education about the virus and Gary expressed hope because he felt legislation against discrimination against people living with HIV had finally caught up. I believe this demonstrated an acceptance of their HIV status and a trust in a continued life.

4.1.5. PSYCHOSOCIAL NEEDS

The psychosocial impact of HIV/AIDS has been noted both pre- (Zich & Temoshok, 1987; Catalan et al, 1992) and post-HAART (Brashers et al, 1999, Siegal & Lekas, 2002; Flowers & Church, 2006). Zich & Temoshok believed that any study of HIV/AIDS should include psychosocial aspects.

The psychosocial issues the men rose during this piece of research concerned money, work, housing and relationships. They talked about what issues they had

[11] Taken from the Bible, in the Gospel of John, Jesus raised a man named Lazarus from the dead. ART was considered to do the same for people with HIV infection.

and how they had gone about resolving then, this had involved the use of support services.

4.1.5.1. Money, work and housing

All of the men talked about issues relating to their finances, work and housing. They had all experienced a dramatic change in their financial circumstances due to living with HIV moving from being financially viable to critical, at certain points during the time they had lived with HIV. This would have added to the sense of hopelessness some of the men felt because they were not able to re-build the lives they had before their HIV diagnoses or they were aware that they would not ever achieved what they thought they would have done prior to diagnosis.

Siegal & Lekas (2002) noted that many infected individuals benefiting from HAART cautiously considered returning to work to improve their finances, become more socially integrated, feel more productive and to contend with boredom. There was uncertainty on how they would cope with work, confronting stigma in the work place and also how they might not feel able to return to work but public perceptions force them to so they aren't perceived as malingering. Duncan had returned to full-time employment, Gary was working part-time, Adam and Brian volunteered for HIV agencies and Callum was undertaking a course in order to return to paid work.

As discussed above, all of the men had to stop work either directly or indirectly because of HIV. The transition from working to living on benefits was difficult from a financial perspective but also considering the men's sense of worth. For many, work did not just provide financial rewards but a social structure and a sense of worth. Gary in particular mentioned enjoying work for the social, as well as financial, benefits.

4.1.5.2. Support

Many of the consequences of living with HIV make social supports important for this population (Green, 1993). People living with HIV with adequate social supports have better mental health (Hays, Turner & Coates, 1992; Kalichman & Sikkema, 1994). It has been suggested that seeking support leads to acceptance of an HIV diagnosis (Leserman et al, 1992; Reeves et al, 1999). Despite all of the above, Weatherburn et al (2007) found that support services were often seen as secondary to treatment and care budgets. This focus on medical provision would appear to have resulted in psychosocial consequences which are unmet considering the high prevalence of depression, suicidal ideation, isolation and this population's use of other maladaptive coping mechanisms. Not all of the men involved with this research had sought out support for these needs, or if they once did, no longer did (discussed further below in section 4.4 Clinical Implications).

The psychosocial needs of gay men living long-term with HIV appeared to be in line with those present for other populations, except with a more chronic presentation. That is, living long term with HIV resulted in fatigue, uncertainty, issues about emotional investment regarding potential friends and lovers. Indeed, the men involved with this study appeared to all present with a low level chronic dysphoria, which was not present for people who have lived shorter-term with HIV, and was likely to increase their psychosocial need.

There are a number of support centers in central Scotland within the NHS but most are in the voluntary sector. All of the men (except for Euan and Gary) talked about how they had, or had not, benefited from the support centers and why they were so beneficial. Brian noted that his mother still used a support center which he found comforting.

4.1.5.3 Relationships

All of the men talked about their relationships with family members, friendships and sexual relationships, and they had all experienced starting new relationships. The men were upfront about their diagnosis to potential new partners. It appeared that if it was considered that sex might happen then disclosing their HIV status was essential, although difficult.

Fear of entering into a new relationship because of concerns of burdening the partner with care-giving responsibilities was discussed by Siegal & Lekas (2002).

Adam and Gary talked about over compensating with new partners to make up for their HIV.

In other literature concerning the psychosocial needs of gay men living with HIV the participants talked about their sexual needs and sexual relationships. The men talked about relationships and the need to disclose their status if a sexual relationship appeared possible, but they did not talk about sex extensively. My gender, age and sexual orientation may well have played a role in this choice of what to disclose to me by the men.

4.1.6 SUMMARY

Whilst the men's individuality was evident in their experience, it was surprising to me that there were such similarity across each of the men's narratives of living long-term with HIV. All of the men talked about their experiences prior to diagnosis, how they reacted when they were first diagnosed, the stigma they felt and issues with disclosure, but the experience of each of the men was individual to them. Brian's initial response was greatly influenced by the reaction he got from others when he disclosed compared to Adam who did not disclose to anyone until he was ready and Gary who denied his diagnosis for 9 years, for example.

Each of the men had physical and mental health experiences due to their HIV but the magnitude and severity has differed between men. Other than the initial ill health at diagnosis, Adam, Brian, Duncan and Gary have kept relatively well compared to Frank and Euan who have had numerous hospital admissions, and for Euan, being told to 'expect the worse' more than once. Mentally Callum and Duncan have considered suicide and all of the men have experienced a degree of depressed mood.
There was an expectation that the introduction of HAART would affect all health problems related to HIV. Physically the results are excellent because people are living but considering psychological state and quality of life issues, the effects have not been as significant.

The men experienced a great deal of loss as a result of their HIV diagnosis. Loss of self, material possessions, status, as well as experiencing the loss of others due to HIV/AIDS. The loss of life was very profound; the men experienced the loss of partners, best friends and of close friends, this appeared particularly pronounced for Euan. Deaths unrelated to HIV appeared to also greatly affect the men but differently from the deaths from HIV.

The men appeared to cope with their diagnosis in similar ways, initially denial, isolation and uncertainty about the future. Over many years they have moved to accepting their HIV using humour, goal setting, altruism, as well as maladaptive mechanisms. A fighting attitude also appeared important and when one was not adopted this meant death. Although the length of time the men utilized a coping mechanism varied. A range of emotions were linked to the virus, including anger, fear, feeling worthless and guilt, or feeling empty as Frank reported.

Being diagnosed with HIV has a complex psychosocial sequalea especially at diagnosis and considering revival, including change in financial circumstance, issues surrounding work, housing, support, relationships and uncertainty. Gary considered legislation effecting those living with HIV.

All of the men accessed support services for themselves and their families, the success of this contact varied between the men. Relationships were an issue for all of the men and choosing when to disclose to a new sexual partner particularly. The men were honest and upfront about their status but knew this was often welcomed with fear, indeed, they appeared to expect it.

4.2 COMPARISON BETWEEN LIVING LONG- AND SHORT-TERM WITH HIV

Currently there is no literature available focusing purely on gay men (or indeed any population) who have lived for a long period with HIV. Literature often focuses on the initial period of adjustment just after diagnosis or on people living with HIV. Therefore are the five themes that emerged from this research with gay men who have lived long-term with HIV relevant to those who have lived for a shorter period with the virus?

Although gay men more recently diagnosed with HIV still experience loss, with HAART they are more able to maintain work and financial security because of increased knowledge about HIV, less stigma and mechanisms in place,[12] gay men are able to maintain or make new relationships or a sex life. Gay men living longer term with HIV can also benefit from these change now but were in a different climate when they sero-converted. The researcher's clinical experience and knowledge of the literature of gay men who have recently sero-converted leads her to the conclusion that all of the themes and sub-themes that emerged from this research are relevant but to differing degrees.

The majority of people who have been diagnosed with HIV experienced the associated stigma and have probably worked through the different stages to reach acceptance including denial, isolation, and uncertainty. They have probably used

[12] Dating magazines and websites exist in the gay community aimed at, or considering, positive men.

similar coping mechanisms including humour, goal setting, support and altruism, and benefited from a positive attitude. Everyone living with HIV will have to deal with the same issues with physical health including medication and probably have similar psychosocial sequelae as a result of their diagnosis.

Uncertainty is uniform for all people now living with HIV. Long-term survivors moved from a certainty of death to uncertainty. Those more recently sero-converted moved into a culture of uncertainty, although hopeful uncertainty, because of advances in medication, treatment options and knowledge of the virus are being made all of the time.

An overwhelming difference between the two populations is death, dying and loss. People diagnosed today would never experience that and not be expected to experience that to the level of men diagnosed pre-HAART, which will affect their adjustment

4.3 LIVING WITH HIV

Many models of coping or adapting to living with HIV have been put forward (Siegal & Kraus, 1991; Reeves et al 1999; Barroso & Powell-Cope, 2000) and they will be discussed below.

Siegal & Kraus (1991) believe that people with HIV had to deal with three adaptive challenges in order to move from denial to acceptance of their HIV diagnosis, as follows:

1.Dealing with the possibility of a curtailed life span (dealing with a sense of urgency to achieve life goals, deciding to what extent to invest in the future)
2.Dealing with reactions to a stigmatizing illness (deciding when to tell about their infection status, dealing with feelings of shame and contamination).

3.Developing strategies for maintaining physical and emotional health (the need to control their health, maintaining appropriate vigilance about their health, treatment decision making, maintaining emotional equilibrium)

After conducting 'in-depth' interviews with 18 HIV+ individuals, Reeves et al (1999) stated that individuals living with HIV went through a period of transition to move from denial to acceptance of living with the virus. During this transition period adaptive strategies were implemented to achieve acceptance, that is, humour, faith, altruism, seeking support from others and balance.

In a metasynthesis of 21 articles published between 1990-1995, Barroso & Powell-Cope (2000) concluded that individuals needed to achieve six objectives in order to accept their HIV diagnosis:

1.Finding meaning in HIV/AIDS-included references of death and dying, other losses and surviving HIV infection.
2.Shattered meaning-HIV represented irreparable and massive losses and led to overwhelming fear.
3.Human connectedness-initiating and sustaining meaningful relationships with friends and family members in the face of increased alienation and separation from others. There is a distinction between two levels of human connectedness, 1. with the larger community and 2. with friends, families and others.
4.Focusing on the self. A set of actions that participants took to enhance both their physical and emotional health. This provided a sense of control over HIV and decreased uncertainty about health matters.
5.Negotiating healthcare-defined as efforts to assume an active role in care. Respondents recognised the need to be responsible for their health and not be passive observers of providers' plans and treatment. They become experts about themselves with regard to medical care

6.Dealing with stigma-involved dealing with reactions to HIV infection on personal, familial and societal levels. People with HIV attempt to protect themselves and families from stigma.

There is a cross over between these pieces of work and between the experiences of the men involved in this research. These pieces of work all concerned research carried out before HAART, so people diagnosed with HIV now would not have had to deal with the prospect of death so overtly.

Barasso & Powell-Cope (2000) discussed human connectedness on two levels- larger community and with friends, family and others. This fitted with the above data, but there appeared to be another aspect concerning human connectedness with the larger community which was different for people who had lived long-term with HIV compared to those who had not.

Considering literature on the guilt felt by some holocaust survivors (Garwood, 1996) it was postulated that guilt could come from two sources, as distinguished by Carmelly (1975), passive carriers who felt guilt about their survival (or those who felt guilt about actual immoral acts). Considering the former, Klien (1984) thought that guilt maintained a link to the holocaust survivors past and those they lost, thereby serving a healthy adaptive purpose in maintaining a sense of belonging to their lost family and to the Jewish people. This could be relevant for people living long term with HIV because being diagnosed before effective treatment meant a lot of loss and death. People who had experienced this might want to maintain their link with what and who they had lost. They need therefore to maintain a distinction as a longer term survivor (rather than a post-HAART diagnosed individual).

Bearing in mind the experiences of the men involved in this study who have lived long term with HIV, and considering the above work, it is thought that there may be two routes gay men living with HIV might progress in order to reach acceptance of their diagnosis. These routes would be distinguishable considering the length of

time they have been living with HIV in terms of when diagnosed in relation to the introduction of HAART. That is, acceptance of HIV could be reached by two routes, a direct route and an indirect route which involves continued identification with the past. This second route might be the route people living with HIV long-term take, which might take more time and involve a more chronic presentation. Movement through to acceptance would involve the use of coping strategies including implementing and maintaining a positive attitude, humour, altruism, goal setting and the realisation that everything is not about HIV, as well as more maladaptive coping mechanisms including alcohol and drug use and suicidal ideation. Continued identification is functional considering identification of the self to the wider HIV + community of gay men so could therefore serve as an additional coping mechanism.

Information gathered from this piece of research suggests that there is a potential difference in the process gay men who have lived longer term with HIV (that is, diagnosed before the introduction of HAART) have to go through to achieve acceptance compared with men who have not lived longer term (that is, diagnosed after the introduction of HAART).

4.4 METHODOLOGICAL CRITIQUE

The aims of this research were to explore the experience of living long term with HIV for the population who are still most likely to become infected, that is, gay men. The researcher had experience working within the field of sexual health but was naïve to this population and had no aspirations to generate a model or theory from this piece of research. IPA fitted with these aspects of the research and allowed for a full account of what it was like for seven men who had lived long term with HIV to be heard and considered as individuals.

Within qualitative research there is always a degree of reduction (Chenail, 1995) which depends on the researcher's own perceptions of what is significant and

noteworthy. One of the reasons IPA was chosen for this piece of research was that it explicitly acknowledges this. Emphasis is therefore put on 'grounding' the data to ensure that its context is preserved and researcher bias is made explicit.
Recent guidance to assure reliability and validity of qualitative research was welcomed and adhered to as closely as possible considering the time and resource constraints apparent during the process of completing this thesis.

4.4.1 LIMITATIONS

-Qualitative Methodology

Qualitative research methods generate a lot of data through the coding process. Open-coding was utilized by the researcher considering an open question. At points the coding and data management seemed overwhelming and infinite. Regular supervision helped the process as well as remaining connected to relevant literature concerning IPA as well as HIV.

-Language Based

A criticism of qualitative research is that it is language based therefore confining the experience to that medium alone, so analysis is dependant on the individuals ability to use language to express themselves. Considering the double hermeneutic it is also dependant on the researcher's use of language. The researcher has tried to paint a full picture of the participants by giving them as much room as possible within this work so their own voices remain evident along with the researcher's interpretation.

-Nonrepresentational Sample

The proposed participants for this research were gay men who had been living with HIV for more than 11 years. They had to have a reasonable level of English, be over 16, not have a learning disability, not have used IV drugs in the past 6 months and not be floridly mentally unwell at the time of the interview. The whole population fitting these criteria in East central Scotland is small. Recruitment occurred through the HIV clinics and support agencies. Although each HIV+ person is invited and encouraged to attend clinic appointments 3 to 6 monthly, the scope of this research may well have not reached everyone. Not all HIV+ people use support services. My research may be skewed to men who use services more often or are more altruistic. A gay man who had adapted well to living with their HIV, and was for example still working, may well have been missed by my recruitment methodology. A longer period of recruitment may well have combated this, but that would not have been possible given the time constraints of this research.

-Researcher Influence

The researcher's age, gender, perceived sexual orientation and profession would have played a role in what experiences the men conveyed, how much detail they gave and in what way experiences were presented. For example, none of the men talked in any great detail about sexual behaviour but did talk about relationships. This cannot be altered but should be acknowledged and reflected upon, as it was, during coding and analyses.

4.5 IMPLICATIONS OF FINDINGS

Green (1993) stated that "there is a need for more qualitative studies to put flesh upon skeletal statistical associations". Working with gay men who had been living

long-term with HIV, their background and experiences may get lost. These results reiterate what it is like, and possible implications of, living long term with HIV which may well not be exposed using other methodologies. Although this type of research is costly in terms of time, the benefits are vast considering the opportunity to share peoples lived experience.

Gay men's experience of living long-term with HIV resulted in five main themes emerging which were consistent with current literature regarding gay men, or individuals[13], living with HIV.

4.5.1 Clinical implications

The importance of considering the psychosocial needs (in both research settings as well as clinically and domestically) of people living with HIV has been well documented. But it has also been suggested that HIV social care, support and information services are often seen as secondary to treatment and care budgets (Weatherburn et al, 2007).

The psychosocial consequences of HIV/AIDS were identified at the beginning of the pandemic for life review work, preparation for death and regarding organic brain disease. Psychology still has a key role within the field in areas such as diagnostic acceptance, treating mental health issues and, more recently, in HIV prevention.

Studies have shown that the rate of new HIV infection is rising and most new infections are seen in the gay male population. The men involved with this research were concerned that HIV was not retaining its 'feared' status. That is, HIV was portrayed as a killer in hard hitting public health campaigns from the mid-eighties to the early nineties. People living with HIV at that time would have internalised a lot of this message and were unwilling for the virus to lose it. They feared that HIV

[13] Consistent with studies carried out in the Western World with men and woman who contracted HIV sexually.

was now seen as a sexually transmitted infection which can be cured with pills rather than the life changing illness it has been for them, with huge biopsychosocial sequelae and still with the real possibility of death. This could lead to people implementing risky sexual behaviour. Studies have shown that psychological interventions can help reduce HIV risk behaviour (Jewkes et al, 2007; Kurtz et al, 2007; Dilley, Woods, Loeb, Nelson, Sheon, Mullan et al, 2007). From a purely financial viewpoint, there are huge costs involved in maintaining an individual on anti-HIV medication for the rest of their life. The costs of a clinical psychologist providing evidence-based HIV prevention therapy are small in comparison.
Gay men living long term with HIV also want to lead a normal life which includes a sex life which has clinical implications.

Isolation, poor housing, low socioeconomic status, no close supportive relationships could all add to a depressive presentation but equally just be seen as part of life for an HIV+ individual, therefore the clinical implications could be missed. The levels of loss experienced by this population could lead to post-traumatic stress disorder, fear of death, and depression. Others may feel they have been left behind or have survivor guilt, for example. All of these demonstrate barriers to treatments in a population with a high morbidity of mental health problems, therefore an individual who has been living with HIV for a long time must be asked about their affect in clinical settings, not just mental health ones.

4.5.2 Implications for service development

This research has highlighted that living long-term with HIV presents specific barriers to services. Individuals might not be able to attend services because of financial issues or due to the severe side effects of the medication, issues which need to be considered when services are developed.
This research has demonstrated an unmet need for gay men living long term with HIV, support groups for long term survivors might be developed and run by long-term survivors for long-term survivors.

Research shows that an individual diagnosed with HIV now, if they go onto medication and live a healthy lifestyle, can expect a near normal life span which has implications for working, relationships and living long-term with HIV. Schemes helping long-term survivors stay at work, return to work, negotiate disclosure, coping with stigma and find relationships, for example, are needed. Indeed voluntary agencies work has moved to a more practical focus because the need is there but this is not coordinated on a National level, so some long term survivors will not benefit.

4.5.3 Future work

It could be hypothesised that acceptance of an HIV diagnosis takes longer for gay men living long-term with HIV because of the loss gay men diagnosed pre-HAART experienced and their relationship to this loss. That is, it may be functional for long-term survivors to maintain a link to those who have died and what they have lost, it has become part of their identity because it was their past. It would be interesting to hear the experiences of gay men who have lived short-term with HIV, using the same methodology, to ascertain how much loss they have experienced and how this has affected them and to see if their experiences fit the proposed model above.

The HIV+ population in the UK is very diverse (Green & Smith, 2004) so any generalisation made from this research to the general HIV+ population would be done with caution (Flowers & Church, 2006). Gay men have a distinct identity part of which has been defined by the HIV/AIDS pandemic which is probably not the case for other populations living with HIV. It would also be interesting to carry out this work with other populations of people living with HIV to see if the themes are relevant for them.

4.6 PERSONAL REFLECTIONS[14]

During the course of this research I kept a reflective diary. It contained my thoughts of the process, it was a space to write my fears as well as research ideas. The main themes which emerged from the dairy are noted below:

-Dual role as a research and a therapeutic clinician in different fields.

I chose a Psychodynamic psychotherapy placement for my final year elective placement on the East of Scotland Clinical Psychology course and my thesis was in the field of sexual health. I had concerns over how the two would fit together intellectually as well as logistically. Psychodynamic psychotherapy fitted well with qualitative methodology in terms of the nature of the interviews and the analytic processes involved with the data. Clinically I knew my commitments and where my thesis would fit and they worked well together, although at times I did feel my head was in two different places.

> "I don't think I would have been so calm at the prospect of the interviews if I had not been working in the psychotherapy department. Before I was not very confident about going into a session without an aim and a direction, whereas now the thought of going in with just one question does not make me want to run away" 22nd January 2007

> "I felt as if a clinical session was 'infected' by my research today, I asked an enquiring question which was slightly leading which I would never usually do". 15th March 2007

-Division between being a therapeutic clinician and an academic researcher.

[14] Personal reflections have been noted throughout this thesis but here some more general reflections will be noted.

Given my academic background I had thought about conducting the interviews from an academic perspective. It wasn't until after I had undertaken the first two interviews that I became aware that there was a conflict between being an empathetic, actively listening academic and a therapist.

> "During the interview I was aware of things popping into my head which I would say in a therapy session which were not appropriate for that setting. I had not really thought about this before, which was daft, because I had thought about how useful my clinical experience would be for the interview"
>
> 3rd March 2007

Once I was aware of this and discussed it in supervision I felt prepared for the next interviews.

-Access to the population

I did not fully realise how difficult it would be to recruit subjects. In the past I have undertaken a number of research projects and recruitment has never been an issue. Whilst preparing the proposal for this project I spoke to two people who had a lot of experience with this population, one clinically the other academically, and they both warned me that recruitment would be problematic.

> "I presented my proposal at the CHIV meeting today and had an opportunity to discuss it, one of the main areas of concern was recruitment. The Consultant Clinical Psychologist in the team thought I would not get anyone to come along to a group, based on her own experience". 4th October 2006

As a result of these discussions I made a substantial amendment to my proposal to gather the data using individual interview.

A lot of time was indeed needed to recruit participants because I had to meet with the different charitable agencies and attend NHS meetings on more than one occasion.

-Emotive contact of the interviews

I knew that the interviews were going to be emotional but I underestimated the actual emotional impact of them. I was surprised at the amount of loss the men had experienced, especially death, and I was amazed at their abilities to keep going and, to some degree, remain positive.

> "Interviewing Frank, very good to talk to him, felt very emotional though. I felt I was opening up areas he kept very tightly shut, but obviously I was not opening them up, he was showing them too me as much as he wanted/could. It felt very emotional and very much about loss and change for the worse".
>
> 11th May 2007

Supervision was used to cope with my response to the interviews and the diary was useful also for more immediate reflection.

5. CONCLUSIONS

It would appear that there is a high degree of similarity in the experience of gay men living long-term with HIV. Initially they denied their diagnosis, felt stupid and ignorant for becoming positive. They all experienced a great deal of loss, of material possessions, of themselves and through death. To move from denial to acceptance of their HIV the men employed a number of strategies. Most were adaptive (for example, altruism, humour, goal setting, adopting a positive attitude, using supports and realising everything was not about HIV) but others were not (for example, contemplating suicide, running away, isolation, continued denial, alcohol and drug use). These men who have lived long-term with HIV appeared to move to accepting their life with HIV along a different route compared to gay men who had not lived so long with the virus. This different route involves considering a functional link to who and what they have lost due to HIV and how this has been internalised as part of their identity as an individual and as a cultural identity as men who have lived long-term with HIV.

There is a big diversity of experience of adaptation to living with HIV, some men adapt well others take a lot longer. It appeared that there were two periods that were particularly difficult for all of the men and these were at diagnosis and revival.

For the men who were involved in this work, the diagnosis of HIV had a complex psychosocial sequalae including depression, suicidal ideation, change in work and finances, difficulty with relationships, living with uncertainty and a change in themselves. This appears to be in line with literature but it would be interesting to ascertain if this was actually the case with future work. Most of the men had an unmet psychological need indicating a continued role for clinical psychology, and ongoing social support services, with this population.

All of the men are now taking HAART but the transition onto the medication was fraught with adapting to regimes, unwanted side effects and the search for the right combination. Generally health care professionals were viewed positively and the men welcomed the introduction of HAART to keep themselves, and others, alive. Each of the men's experiences of living with HIV were individual to themselves but there was a high degree of similarity in all of their lived experiences.

REFERENCES

Avert (accessed 10th June 2007). AIDS timeline. www.avert.org.

Barroso J. (1997) Reconstructing my life: becoming a long-term survivor of AIDS *Qualitative Health Research.* 7: 57-74.

Barroso J. & Powell-Cope G.M. (2000) Metasynthesis of qualitative research on living with HIV infection. *Qualitative Health Research.* 10 (3): 340-353

Bird S. & Brown A. (2001) Crimnalisation of HIV transmission: implications for public health in Scotland. *British Medical Journal.* 323: 1174-1177.

Bishop A (2005) Freeing ourselves from neo-colonial domination in research: a Kaupapa Maori approach to creating knowledge. In: Denzin N.K. & Lincoln Y.S. (Editors) *The Sage Handbook of Qualitative Research* (3rd Edition). Sage Publications.

Bowlby (1969) *Attachment and Loss, Vol. 1.* New York: Basic Books

Brashers D.E., Neid J.L., Cardillo L.W., Dobbs L.K., Russel J.A. & Haas S.M. (1999) 'In an important way, I did die': uncertainty and revival in persons living with HIV or AIDS. *AIDS care* 11(2): 201-219.

Buchanan R.J. (2000) *Homosexuality in history. In: Love, Honor & Respect: How to Confront Homosexual Bias and Violence in Christian Culture.* Writers Club Press.

Callen M. (1990) Surviving AIDS. In: Shernoff M (2006) *Without Condoms: unprotected sex, gay men and barebacking.* Routledge.

Carmelly F. (1975) Guilt feelings in concentration camp survivors? Comments of a survivor. In: Garwood A. (1996) The holocaust and the power of powerlessness: survivor guilt in unhealed wound. *British Journal of Psychotherapy.* 13 (2): 243-258.

Carter D. (2004) Stonewall: the riots that shaped the gay revolution. In: Shernoff M (2006) *Without Condoms: unprotected sex, gay men and barebacking.* Routledge.

Carter M (2005) NAM information services for HIV-positive people: HIV and mental health. www.aidsmap.com

Carter M. (2006) Criminalisation of HIV transmission in the UK: how did we get here and where to now? http://www.aidsmap.com/en/news/1361B904-0D80-420F-B659-71F506446183.asp?type=preview.

Carrico A.W., Johnson M.O., Morin S.F., Remien R.H., Charlebois E.D., Steward W.T., Chesney M.A & the NIMH Health Living Project Team (2007) Correlates of suicidal ideation among HIV-positive persons. *AIDS.* 21: 1199-1203

Catalan J., Klimes I., Day A., Garrod A., Bond A. & Gallwey J. (1992) The psychosocial impact of HIV infection in gay men: a controlled investigation and factors associated with psychiatric morbidity. *British Journal of Psychiatry.* 161: 774-778.

Charmaz K. (2006) *Constructing Grounded Theory.* Sage Publications.

Chenail R.J. (1995). Presenting qualitative data. *The Qualitative Report* [On-line Journal], (2)3. (Accessed 3rd July 2007) http://www.nova.edu/ssss/qr/qr2-3/presenting.html

Chidwick A. & Borrill J. (1998) Dealing with a life-threatening diagnosis: the experience of people with the human immunodeficiency virus. *AIDS care.* 8 (3):271-284.

Ciesla J. & Roberts J (2001) Meta-analysis of the relationships between HIV infection and risk of depressive disorder. *American Journal of Psychiatry.* 158: 725-730.

Cohen M, Hoffman R.G., Cromwell C, Schmeidler J, Ebrahim F., Carrera G., Endorf F., Alfonso C.A. & Jacobson J.M. (2002) The prevalence of distress in persons with Human Immunodeficiency virus infection. *Psychosomatics.* 43: 10-15.

Courtney B.C., Merriam S.B. & Reeves P.M. (1998) The centrality of meaning in transferational learning: How HIV-positive adults make sense of their lives. Adult Educational Quarterly. 48 (2):65-84. In: Reeves P.M., Merriam S.B. & Courtney B.C. (1999) Adaptation to HIV infection: the development of coping strategies over time. *Qualitative Health Research.* 9 (3): 344-261.

DeCock K.M & Johnson A.M. (1998) From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing. *British Medical Journal.* 316: 290-293

Dilley, J.W., Ochitill, H.N., Perl, M., & Volberding, P.A. (1985) Findings in Psychiatric consultations with patients with acquired immune deficiency syndrome. *American Journal of Psychiatry.* 142: 82-86.

Dilley J.W., Woods W.J. & McFarland W. (1997) Are advances in treatment changes views about high risk sex? *New England Journal of Medicine.* 337: 501.

Dilley J.W., Woods, W.J., Loeb L., Nelson K., Sheon N., Mullan J., Adler B., Chen S. & McFarland W. (2007) Brief cognitive counseling with HIV testing to reduce sexual risk among men who have sex with men: results from a randomized controlled trial using paraprofessional counselors. *Journal of Acquired Immune Deficiency Syndromes.* 44(5):569-577.

Dougan S., Elford J., Chadborn T.R., Brown A.E., Roy K, Murphy G, O Noel G., & Dukers N.H.T.M. (2006) Does the recent increase in HIV diagnoses among men who have sex with men in the UK reflect a rise in HIV incidence or increased uptake of HIV testing? *Sexually Transmitted Infection.* 83(2): 120-125.

Fleishman J.A., Sherbourne C.D., Crystal S., Collins R.L., Marshall G.N., Kelly M., Bozzette S.A., Shapiro M.F. & Hays R.D. (2000) Coping, conflictual social interactions, social support and mod among HIV-infected persons. *American Journal of Community Psychology.* 28(4): 421-453.

Flowers P. (2007) *IPA: Introductory Workshop.* Given 19th January 2007 at Glasgow Caledonian University.

Flowers P. & Church S. (2006) An exploratory study of HIV+ gay men and relationships. Connected 1: Testing, Coping and Seeking Support: learning to live with HIV. Healthy Gay Scotland. www.healthygayscotland.com

Flowers P., Church S., Davis M., Marriott C. & Larkin M. (in preparation) Understanding the impact of HIV diagnosis amongst gay men in Scotland: an interpretative phenomenological analysis.

Freud S. (1917) Mourning and Melancholia. In: Holton P. & Millar P (Lecturers) Loss and Berevement. Lecture given 29th April 2005 as part of the University of Edinburgh, Doctorate in Clinical Psychology course.

Garwood A. (1996) The holocaust and the power of powerlessness: survivor guilt in unhealed wound. *British Journal of Psychotherapy.* 13 (2): 243-258.

Gay Men's Health (Accessed 11th July 2007) Sexual Health: HIV and AIDS history of the pandemic (1970s-2000s). www.gmhp.demon.co.uk/health/hiv/history.html

Giorgi A. (1995) Phenomenological Psychology. In: Smith J.A., Harre R. & Langenhove L.V. (Editors) *Rethinking psychology.* SAGE Publications

Green G. (1993) Editorial review: social support and HIV. *AIDS care.* 5 (1): 87-104

Green G. (1995) Attitudes towards people with HIV : are they as stigmatizing as people with HIV perceive them to be? *Social Science & Medicine.* 41 (4):557-568.

Green G. & Smith R. (2004) The psychosocial and health care needs of HIV positive people in the UK: a review. *HIV Medicine.* 5: 5-46.

Gupta A. & Durham R (2007) Cognitive behavioural therapy (CBT) for adults with HIV (Protocol). *The Cochrane Collaboration.* John Wiley & Sons Ltd

Harding R. & Sherr L. (2007) The prevalence, burden and correlates of physical and psychological symptoms in HIV outpatient clinics. Eighth AIDS Impact Conference. Marseilles, abstract 222. (Accessed 15th July 2007) www.aidsmap.com

Harding R. & Molloy T. (2007) Positive features? HIV infection and achieving health, wealth and future planning. Eighth AIDS Impact Conference. Marseilles, abstract 222. (Accessed 15th July 2007) www.aidsmap.com

Hart G., Fitzpatrick R., McLean J., Dawson J. & Boulton M. (1990) Gay men, social support and HIV disease: a study of social integration in the gay community. *AIDS care.* 2: 163-170.

Hays R.B., Turner H. & Coates T.J. (1992) Social Support, AIDS-related symptoms and depression among gay men. *Journal of Consulting and Clinical Psychology.* 60: 463-469.

Herek G.M. (1999) AIDS and stigma. *American Behavioural Science.* 42: 1106-1116.

Herek G., Capitano J.P. & Wildaman K.F. (2002) HIV-related stigma and knowledge in the United States: prevalence and trends 1991-1999. *American Journal of Public Health.* 92: 371-377.

Hickson F., Weatherburn P., Reid D., Jessup K. & Hammond G. (2007) Consuming Passions: findings from the United Kingdom Gay Men's sex survey 2005. *Sigma Research.* www.sigmaresearch.org.uk

IPA (accessed 19th June 2007) What is IPA? www.psyc.bbk.ac.uk/ipa/

Jewkes R. et al (2007) Impact of Stepping Stone on HIV, HSV-2 and sexual behaviour in rural South African youth: cluster randomised control trial with qualitative research. Eighth AIDS Impact Conference, Marseilles, abstract 643. www.aidsmap.com/en/news/OB21E4CB-2F26-464E-A3B3-A3

Kalichman S.C. & Sikkema K.J. (1994) Psychological sequelae of HIV infection and AIDS: review of empirical findings. *Clinical psychology review.* 14 (7): 611-632

Kalichman S.C., Simbayi L.C., Vermaak R., Cain D., Jooste S., Peltzer K. & Habilis D. (2007) HIV/AIDS risk reduction counseling for alcohol using sexually transmitted infections clinic patients in Cape Town, South Africa. *Journal of Acquired Deficiency Syndrome.* 44: 594-600.

King M.B. (1989) Prejudice and AIDS. The view and experiences of people with HIV infection. *AIDS care.* 1: 137-143.

King M. (1997) 'Lazarus Syndrome' perpetuates a new crisis. In: Brashers D.E., Neid J.L., Cardillo L.W., Dobbs L.K., Russel J.A. & Haas S.M. (1999) 'In an important way, I did die': uncertainty and revival in persons living with HIV or AIDS. *AIDS care* 11(2): 201-219

Klein M. (1984) The survivor's search for meaning and identity. In: Garwood A. (1996) The holocaust and the power of powerlessness: survivor guilt in unhealed wound. *British Journal of Psychotherapy.* 13 (2): 243-258.

Kubler-Ross (1969) *On death and dying.* Touchstone.

Kurtz S. et al (2007) Considerations in developing an intervention to bridge serostatus-based social segregation among high risk MSM. Eighth AIDS Impact Conference, Marseilles, abstract 643. www.aidsmap.com/en/news/OB21E4CB-2F26-464E-A3B3-A3

Leserman J., Perkins D.O. & Evans D.L. (1992) Coping with the threat of AIDS: The role of social support. *American Journal of Psychiatry.* 149 (11): 1514-1520.

Lohse N., Hansen A.B., Pedersen G., Kronborg G., Gerstoft J., Sørensen H.T., Vaeth M. & Obel N. (2007) Survival of persons with and without HIV infection in Denmark, 1995-2005. *Annuals of Internal Medicine.* 146: 87-95.

Lutgendorf S., Antoni M.H., Schneiderman N. & Fletcher M.A. (1994) Psychosocial counseling to improve quality of life in HIV infection. Patient Education and Counseling. 24: 217-235. In: Reeves P.M., Merriam S.B. & Courtney B.C. (1999) Adaptation to HIV infection: the development of coping strategies over time. *Qualitative Health* Research. 9 (3): 344-261.

McCain N.L. & Gramling L.F. (1992) Living with dying: coping with HIV disease. *Issues in Mental Health Nursing.* 13: 271-284.

Miller (2003) Marital Status and Living Arrangements. The Scottish 2001 Census (accessed 14th July 2007). www.gro-scotland.gov.uk/statistics/publications-and-data/occpapers/

NAM (accessed 12th July 2007) Treatment and Care: Anti-HIV therapy. www.aidsmap.com

O'Dowd M.A., Biderman D.J. & McKegney F.P (1993) Incidence of suicidality in AIDS and HIV-positive patients attending a psychiatry outpatient program. *Psychosomatics*. 34: 33-40.

Pakenham K.I., Dadds M.R. & Terry D.J. (1994) Relationships between adjustment to HIV and both social support and coping. *Journal of Consulting and Clinical Psychology*. 62 (6): 1194-1203.

Palmer R.E. (1969) *Hermeneutics: Interpretation Theory* in Schleirmacher, Dilthey, Heidegger & Gadamer. Evanston, IL: Northwestern University Press.

Préau M et al. *Health*-related quality of life in French people living with HIV in 2003: results from the national ANRS-EN12-VESPA Study. *AIDS* 21(suppl 1): S19–S27, 2007.

Rabkin J.G., Ferrando S.J., Lin S.H., Sewell M. & McElhiney M. (2000) Psychological effects of HAART: a 2-year study. *Psychosomatic Medicine*. 62: 413-422

Reeves P.M., Merriam S.B. & Courtney B.C. (1999) Adaptation to HIV infection: the development of coping strategies over time. *Qualitative Health Research*. 9 (3): 344-261.

Reid K., Flowers P. & Larkin M. (2005) Exploring lived experience. *The Psychologist*. 18 (1): 20-23.

Richardson A. & Hewitt C. (2006) *HIV and Clinical Psychology*. Lecture given 20th November 2006 for the East of Scotland Doctorate in Clinical Psychology Course.

Shaw R.L. (2001) Why use interpretative phenomenological analysis in health psychology? *Health Psychology Update*. 10 (4): 48-52.

Shernoff M (2006) *Without Condoms: unprotected sex, gay men and barebacking*. Routledge.

Siegal K. & Krauss B.J. (1991) Living with HIV: adaptive tasks of seropositive gay men. *Journal of Health and Social Behaviour*. 32 March: 17-32.

Siegal K & Lekas H. (2002) AIDS as a chronic illness: psychosocial implications. *AIDS.* 16(4): s69-s76.

Shilts R. (1987) *And the band played on: politics, people and the AIDS epidemic.* Penguin books.

Smith J.A. (1995) Semi-Structured Interviewing and Qualitative Analysis. In: Smith J.A., Harre R. & Langenhove L.V. (Editors*) Rethinking psychology.* SAGE Publications

Smith J.A., Harre R. & Langenhove L.V. (1995) *Rethinking Psychology.* SAGE Publications.

Smith J.A. (2003) *Qualitative Psychology: A practical guide to research methods.* SAGE publications

Smith J.A. & Osborn M. (2003) Interpretative Phenomenological Analysis. In: Smith J.A. (Editor) *Qualitative Psychology: A practical guide to research methods.* SGE Publications.

Telford K., Kralik D. & Koch T. (2006) Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing.* 55 (4): 457-464.

Thompson (2003) Lazarus Phenomena: An Exploratory Study of Gay Men with HIV/AIDS. Making sense of death and dying. Second global conference. (Accessed June 29th 2007) http://www.inter-disciplinary.net/mso/dd/dd2/s6b.htm

Vailliant G.E. (1977) Adaptation to life. Boston: Little, Brown. In: Reeves P.M., Merriam S.B. & Courtney B.C. (1999) Adaptation to HIV infection: the development of coping strategies over time. *Qualitative Health Research.* 9 (3): 344-261.

Vass A. A. (1986) *AIDS: A Plague in us, a social perspective.* Venus Academia.

Vital Statistics (2007) The UK gay men's sex survey: Scotland NHS Health Board's data report (April 2007). *Sigma Research* www.sigmaresearch.org.uk

Weatherburn P., Keogh P., Dodds C., Hickson F. & Henderson L. (2007) The growing challenge: a strategic review of HIV social care, support and information services across the UK. *Sigma Research* www.sigmaresearch.org.uk

Weitz R. (1989) Uncertainty and the lives of persons with AIDS. *Journal of Health and Social Behaviour.* 30: 270-281.

Willig C. (2001) *Introducing Qualitative Research in Psychology: Adventures in theory and method.* Open University Press.

Wolcott D.L., Namir S., Fawzy F., Gottlieb M. & Mitsuyasu R. (1986) Illness concerns, attitudes towards homosexuality, and social support in gay men with AIDS. *General Hospital Psychiatry.* 8: 395-403.

Worden J. W. (2003) *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner.* Routledge.

Yardley L. (2000) Dilemmas in qualitative health research. *Psychology and Health.* 15: 215-228.

Zich J. & Temoshok L. (1987) Perceptions of social support in men with AIDS and ARC: Relationships with distress and hardiness. *Journal of Applied Social Psychology.* 17 (3): 193-215.

APPENDICES

APPENDIX 1 List of agencies involved in this study.

- Voluntary Agencies:

SOLAS
Waverley Care SOLAS
2-4 Abbeymount
Edinburgh EH8 8EJ.
0131 661 0982

Positive Voice
37-39 Montrose Terrace
Edinburgh EH7 5DJ
0131 652 0754

Positive Help
13a Great King St
Edinburgh EH3 6QW
0131 558 1122

Gay Men's Health
10a Union Street
Edinburgh EH1 3LU
0131 558 9444

Healthy Gay Scotland
Healthy Gay Scotland
Suite 2, Beaverhall House
Beaverhall Road
Edinburgh EH7 4JE
0131 558 3713

- NHS agencies:

GUM clinic
Department of Genitourinary Medicine
Level 1
Lauriston Building
39 Lauriston Place
Edinburgh EH3 9HA
0131 536 2103

CHIV team
Community HIV team
Spittal Street Centre
22-24 Spittal Street
Edinburgh EH3 9DU
0131 537 8300

RIDU
Regional Infectious Diseases Unit
Western General Hospital
Crewe Road
Edinburgh EH4 2XU
0131 537 2841

APPENDIX 2 Poster

Are you a Gay Man who has been living with HIV for 10+ years?

Do you have relationship issues, anxiety, depression, social concerns?

Are these needs being met?

Would you like the opportunity to state what problems/needs you have and if they are being met?

If so, I am currently undertaking research in this area and would like to hear from you.

Please contact Alison Wells (Trainee Clinical Psychologist) on: 0131 537 8300 or email me at: aliwidge@hotmail.com

Or let a member of staff know that you are interested.

Thank you and I look forward to meeting with you.

NHS
Lothian

APPENDIX 3 Information sheet

The Spittal Street Centre
22-24 Spittal Street
Edinburgh
EH3 9DU

NHS
Lothian

The psychosocial needs of gay men living long-term with HIV
Patient Information Sheet

(Version 2 11.1.07)

You have shown an interest to take part in a survey to find out what psychosocial needs gay men who are long-term (10+ years) HIV positive have, and if these needs are being met. Before you decide to take part, it is important for you to understand why this research is being undertaken and what it will involve. You can ask for more information at any time and you can change your mind and withdraw at any stage.

What is the purpose of the survey?
I want to find out the opinions of people who have lived long-term with HIV to see if they have any psychosocial needs and if these are being met. The purpose of this work is to hear individuals' accounts of their experience, in their own words. We would meet individually and then, possibly, in a group with other gay me who have lived long-term with HIV. We might talk about how you contracted the virus, how it has been living with it considering your family, friends, relationships, work etc. The interviews (and group) will be recorded, transcribed (typed out from the tape), then analysed by me.

What are psychosocial needs?
The term 'psychosocial' refers to any issues which are not generally considered to be covered by medical, physical or biological. They tend to include things like anxiety and depression (i.e. psychological issues) or relationship issues and work problems (i.e. social issues).

Why have I been chosen?
You have been chosen to be approached to take part in this study because you are a gay man who has lived for at least 10 years with the HIV virus.

Do I have to take part?
No. You do not have to take part. If you decide not to, your care will not be affected in any way. If you decide to take part you are still free to drop out of the study at any stage without giving a reason. This includes your right to stop part way through an interview (or the focus group). If you do decide to take part, you will be asked to sign a consent form giving your agreement to take part.

What do I have to do?
If you are interested in taking part please contact me using the address, telephone number or e-mail address indicated on the bottom of this sheet. Once you have indicated you would like to be involved in this study, you will receive a letter with details of the interview on it and contact details, and a consent form, which you need to sign and bring with you to the interview.

If you would like to be involved but have concerns or questions please contact me.
At the interview (and the focus group) you will be asked to discuss your experience of any psychosocial needs and how these have or have not been met. This might include discussing how you felt about your HIV diagnosis, finding out about services, what happened when you contacted them or issues in other aspects of your life. The interview (and focus group) will run for about an hour to an hour and a half.

What happens to the information I give during the interview and focus group?
The interview and focus group discussion will be tape recorded so that I can listen to what was discussed without the need to take excessive notes during it. Following the discussion it is typed up from the tape. Your personal details, any names of people or places mentioned will remain confidential, as they will not be included in the subsequent report. The written information will be stored securely and only 2 authorised staff will have access to the information.
Your confidentiality will be protected but during the focus group I can only guarantee that I will maintain confidentiality, and that confidentiality must be agreed and respected by the individuals within the focus group. If the discussions revealed that you or somebody else was at risk of harm (for example, from a partner), I would have to share this with colleagues. I would only breach your confidentiality if there was a risk of serious harm to you or somebody else.

What happens to the tape recording of the interview and focus group?
After the tapes have been analysed and the report has been written, the tapes will be deleted.

What will happen to the results of the survey?
The report will inform and guide people who have an interest in this area (in and out of the NHS) about the psychosocial needs of gay men living long-term with HIV and if these needs are being met.
Also, this research will form part of the work I need to undertake in order to fulfil requirements for a course I am currently undertaking in order to become a clinical psychologist.

Who has approved the survey?
The survey has been approved by an NHS local Research Ethics Committee and the University of Edinburgh's, Department of Clinical and Health Psychology, Course Organisation Group.

What if I want to make a complaint?
If at any point you would like to make a complaint, please contact a member of the CHIV team; Dr Alison Wells, Trainee Clinical Psychologist; Dr Chris Hewitt, Clinical Psychologist, GUM clinic, Lauriston building, Edinburgh or Dr Alison Richardson, Consultant Clinical Psychologist, CHIV team, Spittal Street Centre, 22-24 Spittal Street, Edinburgh.

Contact for further information
Dr Alison Wells, Trainee Clinical Psychologist, The Spittal Street Centre, 22-24 Spittal Street, Edinburgh EH3 9DU. Tel: 0131 537 8300. Email:aliwidge@hotmail.com

APPENDIX 4 Consent form

The Spittal Street Centre
22-24 Spittal Street
Edinburgh
EH3 9DU

NHS
Lothian

The psychosocial needs of gay men living long-term with HIV.

CONSENT FORM

Full details of this study are contained on the information sheet – The psychosocial needs of gay men living long-term with HIV.

Anything you tell me will be treated anonymously – your name will not be passed on to anyone else and any records kept of our discussions will not have your name, or any other identifiable information, recorded on them.

The experiences that you describe will be used for three purposes:

1. To help us learn what is important to individuals living long-term with HIV
2. To help us to improve services
3. To be part of my Clinical Psychology assessment portfolio

There is no pressure on you to take part in this process. If at any point (including while being part of the interview or focus group) you wish to stop then you simply need to say so.

For our records – to show that you understand the work we are doing and to show you are happy to take part – please respond to the statements as appropriate below:

I have read and understood the information sheet	Yes/No
I have been given the chance to ask questions about this study	Yes/No
I know I can withdraw at any time	Yes/No
If I take part in the focus group, I will respect and maintain the confidentiality of other participants taking part in the focus group.	Yes/No
I consent to participate in this research	Yes/No

Signature..... Witness signature.....

Name..... Witness name.....

Date..... Witness Date.....

APPENDIX 5 Section of coded transcript

Emerging themes

Exploratory codes

Death of everyone
Funerals

Death of everyone
Everyone dies of HIV
Life before HIV
Social isolation/limits
To reduce loss

Coping
Certainty/uncertainty
Life before HIV

Avoiding denial

Receiving diagnosis

Medication

Living with HIV

Identification of self
Outwith HIV

Life before HIV

Life before HIV
Identity

Impact of HIV

Self identity

Changes due to HIV

That period, the whole period from before M died, like sort of eighty, late eighties, right through until 2000, it was like a mini holocaust. The number of deaths and the number of funerals I went to was just unbelievable. Just about all the friends I had died except one who isn't positive at all and it was good because I got to the point, I thought, I didn't know anyone who was positive, I thought good because there will be no more funerals.

Comment: Death, pain, lack of dignity, life taken

Comment: Everyone with HIV dies

A Right, so there was definitely a link there

Comment: Coping with loss by isolation, acceptance of the losses, funerals represent the loss

S Yeah. But it um, just a few months after M died, I thought I am going to get tested, I don't want to do what M did, I want to know now, I don't want to go through what he went through. So literally he died in the April and I got tested in the August and it came back positive. I said immediately I want to go on the medication and I went on the medication. So right from then on and we were talking [redacted] on, it has been one hell of a roller-coaster. I'm trying not to make this whole conversation about that, but it has had such an impact, that I've forgotten what my life was like before. I just know I didn't seem to have any problems, I know I lived in a nice house, money wasn't a problem, I had a good job, I was earning good money and yeah, it was privileged and a very good life.

Comment: Didn't want to deny status, avoidance of uncertainty

Comment: Partner's approach was wrong-guilt? Defiance of partner?

Comment: Diagnosis

Comment: Immediately had to do something, react to diagnosis, opposite to partner's reaction, denial/acceptance?

Comment: Loss of control with diagnosis?

Comment: I am not just about HIV, sense of self

Comment: But cannot define self without considering HIV

Comment: Life before HIV good therefore difficult not to see HIV as bad, negative

A From what you've said growing up sounded very rich and enjoyable, fulfilling and challenging.

S Yeah, and a lot of my energy went into my work, all those years from 76, yeah right through to 2002 when I gave up [redacted]. That first part or so covered the first year of [redacted], training and the year after qualifying. So for a long time [redacted] was a big, big part of my life and [redacted] was a big part of my life, but not for the first 5 years I've been back in [redacted]. Being back in

Comment: Poor sense of self, need to define self through work? Good moral values, work hard? Work equals an identity, lost without it, self -esteem

Comment: Adjustment to living in Scotland, leaving the good stuff behind, returning a failure?

Living with HIV

Relationships
Social isolation
Fear/loss
Death not from HIV

Loss
Altruism?
Maladaptive coping?
Death not from HIV
Uselessness/worthless
ess
Housing issues/money
Harrassment, stigma?

Loss of possessions
rough theft

Maladaptive coping-
voidance

Coping adaptively

Living-everything not
st HIV
Loss of mother
Anxiety
Loss

Funerals, isolation,
oping

No support

Uncertainty

Altruism?
Accepting the job for
e sake of others

No support
Anger
Coping with the loss

[redacted] has been one, one, a tough, tough, tough, I'm going to use that word again, rollercoaster.

I've been single ever since M died and I've not met anyone since M died. I don't know why, well I've got my theories of why. But since coming back to [redacted], 4 weeks after my sister died suddenly and then for the next years um, I made, I was back partly to help to look after my mother who was in the [redacted] for 7 years and then last year my mother passed away in the January. And in between all that I was housed in probably one of the worst parts of Scotland. Now I didn't know that but I had a lot of problems with harassment both verbal and physical, and eventually, after over3 years, I had to get re-house. I had a car stolen, now I don't own a car, there just seemed to be one thing after another, after another. I kept thinking I'll go back to [redacted], I'll go back to [redacted], anyway I didn't go back. I didn't even go back for a holiday even though I did plan one once but pulled out at the last minute. As I say, my mother's health was starting to deteriorate about 9 months before she died, then it was all very quick. That was last, then, then about 4 months later my younger brother became ill, he recovered from that, then in the November he died suddenly. Now, how I landed the job I don't know, but I arranged all 3 funerals and did a lot, I was involved with everything with all 3, but with my brother I was left to do literally everything you have to do. Now I've never been in a position where I've had to do everything where there was no one else wanting to do anything or offering to do it.

A How did you find that?

S Well, it kept me occupied and I did it for D's sake and I didn't mind doing it at all and I didn't, initially I thought I would be offered some help but it never came. I thought if no one else is going to do it, I'll do what has to be done I said to myself. So I literally did everything and it was only been in

Comment: Emphasising the tough journey for him since diagnosis

Comment: Isolation, no sexual (or other?) relationships

Comment: Not telling me everything, keeping things back

Comment: Sudden death of sister, not HIV

Comment: Helping others, who helps him?

Comment: Death of mother, loss of role

Comment: Poor housing compared to good house in the past

Comment: Harrassment, stigma, isolation, effect of mental health?

Comment: Loss of possessions, theft, loss of self?

Comment: AS if living with HIV wasn't bad enough

Comment: Running away? Wanting his life pre-HIV?

Comment: Cannot go backwards, acceptance?

Comment: Given a role because of mother's health; avoidance?

Comment: Brother suddenly ill then died; loss, me next?

Comment: Why do these things happen to me?

Comment: Arranging all funerals with no support, he copes with death

Comment: Did everything for brother, who will do everything for me?

Comment: Who will care when I die?

Comment: Did the job for brother

Comment: Surprise no help was offered, do they care?

Coping with loss

Dying with dignity?

Arranging funerals for family

No more funerals, own funeral?

Loss of role/identity

Helping brother

Overall effect of so many deaths in family

Deaths still occur

Transitions in life
Coping

Difficulties with relationships
Using support services

Making friends

Receiving support

the past 2 weeks, that I've dealt with the final part which I felt had to be done, which was to meet with the Doctors, thank them and hand them over a cheque that we had collected at my brother's funeral. And that was only done two weeks ago and that was the final part, well part I felt had to be done. But I did everything with his house, arranged his funerals, I gave all the eulogies at all 3 funerals because no one else will do it. After my brother I thought that's it. I thought the rest of you are married, well I said to myself, if I've not said to them, I'll not have to go through that again because they've all got wives or husbands or partners and blah blah blah. Whereas my brother he didn't, he was separated for a long time, it really was one of us who had to do what had to be done. His death hit me a lot harder than my mother's death or my sisters, I don't know if it's a cumulative effect, but it's still very, very, it still feels very, very raw. It' been what 3 ½ months, well no 4 months on the [redacted], so we are almost 4 months

A Yes but not long though

S November, December, January, February, March, yeah, 4 months nearly

A But to use your words, there have a lot of deaths, and I was wondering if it was the end of the rollercoaster?

S Yes, that's right, um, and in the 5 years I've been back I've been back here 5 years on [redacted] not that I'm counting, I just remember the date, um, things have happened. I've not made, I've found it difficult to make friends so I've not made a single friends. I got involve with the [redacted] that [redacted] have and I've had two terrific [redacted], well they were actually the [redacted], and so I never went though the process of what you do to get [redacted]. I just met the [redacted] and we just kind of followed on from there. The last [redacted] I had was terrific at helping me through the two deaths I had last year, um, and he was a terrific person and ended up, we

Comment: Is this the end of the death? Who next? Will it be me next?

Comment: Doing it properly, dying with dignity

Comment: Having to do everything re: brother's death, who will do this for him

Comment: No more death

Comment: I'm not doing dearth any more

Comment: Death has become mundane?

Comment: Brother isolated like him

Comment: Similarities with brother

Comment: I've seen so much death why does it still affect me

Comment: Difficult coming back, been a long time and not achieved aims for returning

Comment: Difficult making friends, disclosure, stigma, starting again, is it worth it because I'm going to die?

Comment: Using support services to make friendships

Comment: Recognising that others can be helpful, don't have to be alone

Relationships

Support
Loss

When support doesn't work
Deciding not to persue a relationship-isolation
Loss

Living with HIV
Loss?

Uncertainty about the future
Family relationships
Resentment?
Worthlessness
Knowing self

Disclosure
Acceptance
Keeping mentally well
Support
Stigma?
Lack of support
Isolation

Disclosure

Stigma

Medication
Living with HIV
Coping

were good friends long before he left in January to go and live in the [redacted]
And then I applied, I had to go through the proper process and I didn't particularly like the person, so I thought no, I don't want to do this it feels to manufactured, I don't want a manufactured friend. I did meet the person then I said to the new [redacted] I just want to forgot it, I'll be alright. I do miss the chats I had with my [redacted] my friend, D, that I had before. Things change and, but for me, I don't feel that, I don't know where the last 5 years have gone and, and a lot of the. I did come back with expectations, and friends in [redacted] said don't expect this, don't expect that, don't expect your family to be this way and that way, and of course I did. The first year was , there were a lot of, well they said, that I've been told that everything was nice and peaceful until I came back. That I provoked a few of my brothers and one sister in particular, who now I don't see. I just see one brother and one sister and now there are only [redacted] of us, so basically I see one brother once or twice a week and one sister I see if I go and visit her. They've known from day one that I am positive but they have never ever, to this day, [redacted] how is you with the HIV
A Right
S I don't know if they are uncomfortable with it or they think I'm going to be uncomfortable with it. Um, so it's, I cannot go to them to talk about it. There was one situation where, I mean I don't like hiding it, but I don't go about shouting it from the roof tops because you've got to be careful, you know what I mean because there is a huge stigma attached to it. I was at my brothers one night and he said have a meal, stay for a meal, and I knew I had to take pills after food.

Comment: More loss, everyone leaves

Comment: Cannot replicate past experiences so don't try only ends negatively

Comment: I don't need others, isolation

Comment: How have there been 5 more years?

Comment: Unmet need

Comment: Loss of place in the family, no role in family, outsider, stigma?

Comment: Family discord

Comment: Family contact on their terms, his needs are unheard and unmet, lonely?

Comment: No support with his issues i.e. HIV

Comment: Making excuses for his families behaviour, helping them out. Role of stigma, denial and avoidance?

Comment: Family not there to support him

Comment: Accpetance of status but still need ofr care when disclosing due to stigma

Comment: Taking pills reminder of status for self and others.

APPENDIX 6-Group emergent themes and sub-themes
(For individual themes see contents)

1. DIAGNOSIS
    - Life before HIV
        - Life before their HIV diagnosis
        - Hearing about HIV before becoming positive.
        - Circumstances leading up to their diagnosis:
        - Reaction to diagnosis
    - Stigma
        - Some of the men had directly experienced abuse,
    - Disclosure
        - Anger, anxiety and tension of disclosing.
        - Disclosing sexuality and HIV status

2. HEALTH
    - Physical Health
        - Co-morbid physical conditions with HIV:
        - Opinions of medical professionals:
        - Experience of being a carer and being cared for:
    - Medication
        - The introduction of ART
        - Getting the right combination
        - Unwanted effects of medication
        - Long term effects of the medication:
    - Mental health
        - Depression
        - Suicide
        - Keeping mentally well

3. LOSS
    - Loss of self
    - Loss of possessions and status
    - Death
        - HIV equals death
        - Death of a partner
        - Dying but not from HIV
        - Funerals
        - Consequences of death
        - Preparing for death

4. LIVING
    - Coping
        - Denial
        - Isolation
        - Uncertainty about the future
        - Goal setting for living
        - Altruism
        - Using humour to cope
        - Maladaptive coping mechanisms
        - Acceptance (including learning to trust in life)
    - Attitude
        - Adopting a fighting attitude is adaptive
        - Deciding to live
    - Emotions
        - Anger/resentment
        - Worthless and useless
        - Fear
        - Guilt
    - Living with HIV

5. PSYCHOSOCIAL NEEDS
    - Money, work and housing issues
    - Support
        - HIV support centres
    - Relationships
        - Meeting new people/a new partner

APPENDIX 7 Ethical approval letter

Lothian NHS Board

Dr Alison Wells
Trainee Clinical Psychologist

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9009
www.nhslothian.scot.nhs.uk

NHS Lothian

06 February 2007

Lothian Local Research Ethics Committee 01

Telephone: 0131 536 9050
Facsimile: 0131 536 9346
Email: elaine.racionzer@lhb.scot.nhs.uk

Dear Dr Wells

Full title of study: **The pychosocial needs of gay men living long-term (10+years) with HIV**

REC reference number: **06/S1101/53**

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting the revised documentation.

The further information was considered at the meeting of the Committee held on 31st January 2007.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. I will write to you again as soon as one Local Research Ethics Committee has notified the outcome of an SSA. In the meantime no study procedures should be initiated at sites requiring SSA.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		08 November 2006
Investigator CV		
Protocol	1	07 November 2006

Covering Letter	2	11 January 2007
Covering Letter		08 November 2006
Letter from Sponsor		06 November 2006
Advertisement	2	11 January 2007
Letter of invitation to participant	1	01 November 2006
GP/Consultant Information Sheets	1	11 January 2007
Participant Information Sheet: PIS	2	11 January 2007
Participant Consent Form: Consent Form	2	11 January 2007
Insurance Details		28 July 2006
Flow Chart	2	02 November 2006
Semi-structured Interview	1	03 November 2006
Reference List		

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the NHS Lothian R&D Group.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/S1101/53 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely
pp

Mr Nicholas Grier
Chair

Email: elaine.racionzer@lhb.scot.nhs.uk

Enclosures: *Standard approval*
Site approval form

Copy to NHS Lothian R&D Group

APPENDIX 8 R&D letter

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

HAC/SM/approval/Wells/2e

28th February 2007

Dr Alison Wells
Trainee Clinical Psychologist

NHS Lothian

RESEARCH & DEVELOPMENT OFFICE
Room E1.12

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PA to Professor Cubie & Dr McLelland:
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Dr Janet Hanley

Research Governance Co-ordinator:
Mrs Susan Shepherd

Information & Knowledge Manager
Miss Heather Cowpar

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Administrative Assistant:
Ms Sandra Muir

St John's – Administrator:
Mrs Anne Addison

Dear Dr Wells

MREC No:	N/A
CRF No:	N/A
LREC No:	06/S1101/53
R&D ID No:	2007/P/PSY/06
Title of Research	The psychosocial needs of gay men living long term (10+years) with HIV
Protocol No/Acronym:	N/A

The above project has undergone an assessment of risk to NHS Lothian and review of resource and financial implications. I am satisfied that all the necessary arrangements have been set in place and that all Departments contributing to the project have been informed.

I note that this is a single centre study sponsored by University of Edinburgh.

On behalf of the Chief Executive and Medical Director, I am happy to grant management approval from NHS Lothian to allow the project to commence, subject to the approval of the appropriate Research Ethics Committee(s) having also been obtained. You should note that any substantial amendments must be notified to the relevant Research Ethics Committee and to R&D Management with approval being granted from both before the amendments are made. Please note that this approval covers Amendment No1 dated 11th January 2007.

Please note that under Section A, Q35, NHS Lothian provides indemnity for negligence for NHS and Honorary clinical staff for research associated with their clinical duties. It is not empowered to provide non-negligent indemnity cover for patients. NHS Lothian does not provide indemnity against negligence for healthy volunteer studies. This is the personal responsibility of both NHS and honorary employees and is usually arranged with a medical defence organisation or through the University of Edinburgh.

This letter of approval is your assurance that NHS Lothian is satisfied with your study. As Chief Investigator or local Principal Investigator, you should be fully committed to your responsibilities within the Research Governance Framework for Health and Community Care, an extract of which is attached to this letter.

Yours sincerely

Professor Heather A Cubie
R&D Director

Enc
- Research Governance Certificate — ☑ (to be signed and returned)
- NRR authorisation — ☐ (to be signed and returned)
- Tissue Policy (if applicable) — ☐
- MTA (if applicable) — ☐ (to be signed and returned by the recipient)

Copies *Administrators, Research Ethics Committee*
Dr Chris Hewitt, Clinical Physcologist, Lauriston Buildings